

MS Professional

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www.ukmssna.org.uk



Need help and support? The UKMSSNA is here for You!

Most of us love our job and role of MS nurse involving MS patients; if only that was all we had to worry about!! MSSNs are a very special group and via our website we share excellent practice with protocols, care plans, slide library and audit of role. As a group we are great at answering each other's queries through Mary and the fabulous email system. Through conferences a great deal of networking goes on and we can let our hair down and relax.

As a group, MS nurses nationwide are the most supportive professionally and in practice that I have ever met. That's what makes us so special.

However, recently I have heard that some MS nurses are still working alone, feeling overwhelmed or new in post and don't feel comfortable asking for information/ advice or just reassurance. This leads to increased pressure within the workplace, stress and time off sick.

I am honoured to be your Chair of UKMSSNA, BUT remember this is *your* group and *your* success!!

Please do not feel alone - we now have representatives for all your regions – use them, contact them or me. We may not be able to help directly with the work situation but a problem shared, sometimes to somebody not directly in the situation, can help to reduce the pressure. It may be beneficial just to pick up the phone or email (although the people that know me also knows it may take some time to reply to email!) for a chat, reassurance, banter, discuss an idea or a moan.

Remember you all do a fantastic job and often managers are totally unaware of exactly what you do. Tell them and you may be surprised (we were!).

One last request, if you know anybody that has been off work for 4 weeks or more, please let us know and at least we can send a card to let them know we are thinking about them.

Keep up the good work!

The **UKMSSNA AGM** will once again be held on the first evening of the MS Trust Conference – 6.00pm Sunday 2nd November – at the Queens Hotel in Leeds.

The Agenda and Minutes of last year's meeting are on the UKMSSNA website (follow the link from the Home page).

A Practical Guide to NAb Testing in the UK is now available

Most clinicians are fully aware of the significance of NAb and a number of centres in the UK have begun routine testing. What is less certain for many professionals are issues such as when to test, how to test, the financial impact of testing, the significance of the findings and the effect on patient decisions regarding treatment. This guide includes an overview on the rationale for testing and the use of counselling such that an explanation should be given as clearly as possible and be routine practice for every patient starting interferon-beta.

The clinical significance of NAb in multiple sclerosis treated with interferon-beta has been demonstrated by a number of studies. There is a growing body of evidence showing the development of NAb may significantly reduce or negate the benefits of interferon-beta in some patients. These findings have been further supported by the publication of guidelines from the European Federation of Neurological Societies (EFNS), the American Academy of Neurology (AAN) and the Association of British Neurologists (ABN) - all of which make reference to the NAb testing of patients treated with interferon-beta.

With this in mind a guide has been developed by an expert working group consisting of a cross-section of neurologists and MS nurse specialists which seeks to provide:

- a review of the clinical evidence to date
- a summary of the published guidance on NAb testing
- practical advice on how to manage the testing process - initiating a protocol, undertaking the test and counselling patients.

MS Specialist Nurse and UKMSSNA Committee Member Alan Izat, who helped to develop the guide, explains. "I work in a Prescribing Centre that has been involved in routine testing for NAb since April 2006 and I was pleased to take part in the

interdisciplinary working party looking at NAb and NAb testing. This professionally and geographically diversified group examined the data closely and came to a consensus about the provision of clear advice on how to test from a local perspective."

Members of the expert group which developed the guide were:

Professor Gavin Giovannoni, Consultant Neurologist, Institute of Cell and Molecular Science, Barts and The London School of Medicine and Dentistry, London

Dr Jacqueline Palace, Consultant Neurologist, John Radcliffe Hospital, Oxford

Dr Tom Staunton, Consultant Neurologist, Norwich and Norfolk University Hospital, Norwich

Dr Rachel Farrell, Clinical Research Fellow, Institute of Neurology, UCL and Institute of Cell and Molecular Science, Barts and The London School of Medicine and Dentistry, London

Dr Viki Worthington, Principal Clinical Scientist, National Hospital for Neurology and Neurosurgery - Queen Square, London

Dr Paul Creeke, Post-doctoral Scientist, Institute of Cell and Molecular Science, Barts and The London School of Medicine and Dentistry, London

Megan Burgess, MS Nurse Consultant, Hope Hospital, Greater Manchester

Gail Hayes, MS Clinical Nurse Specialist, Mardon Neurological Rehabilitation Centre, Exeter

Alan Izat, MS Specialist Nurse, Ayrshire Central Hospital, Irvine, Ayrshire

The guide is available from your local Teva Pharmaceuticals rep. or call 01296 719768.

BJN Awards

Our belated congratulations to members Maureen Speed and Susan Holmes for their success in winning the BJN MS Nursing Award back in May. They won the award for service development at a time when some specialist nurses posts were at risk. Maureen said "in collaboration with the neurologists we have taken over the management of the majority of the MS patients in East Kent, which has had a knock-on effect of freeing up outpatient appointments with the neurologists and has been cost effective.



GLAMS is a national support group for LGBT (lesbian, gay, bisexual and transgender) people affected by Multiple Sclerosis. It strives to create an environment where neither sexuality nor health is an issue, but instead is recognised as an integral part of our lives.

GLAMS aims to raise awareness of MS within the LGBT community by providing information and offering advice and support. Backed by the MS Society and with membership across the UK, we aim to establish a welcoming space for people to interact, seek support and make connections with people in similar situations.

We produce a quarterly newsletter, *The Glamster*, with news about both MS and the LGBT community, and also provide regular opportunities for our members, partners and friends to meet socially, locally and across the country, both online and in person. We provide a forum which offers support, provides an opportunity to share experiences and breaks down barriers to tackle isolation within the LGBT community.

The MS Society has a GLAMS telephone helpline and the GLAMS message board provides a source for online contact, discussion, fun, advice and information about issues affecting the LGBT community. We are here and already making a difference.

Helpline: 0208 438 0959 (Monday to Friday 10am-3pm)

Email: glams.uk@gmail.com

Message Board Link:

www.mssociety.org.uk/glams



The UKMSSNA and Pharmaceutical Companies

The UKMSSNA acknowledges the support received from the four pharmaceutical companies – Biogen Idec, MerckSerono, Bayer Schering Pharma and Teva Aventis. The UKMSSNA receives educational grants for committee meetings and for many of our working party (Slide Library, Protocols and Pathways, etc.) meetings.

On a less positive note, several members have expressed concern about contact from market research companies and a company conducting a clinical trial. The committee had a lengthy discussion about this at their September meeting and Kerry Mutch, Chair of the UKMSSNA, will be writing to various companies about unsolicited contact with MS Nurses to obtain referrals and patient information or to help with market research.

Policy on circulating commercial information

From time to time the UKMSSNA receives requests to circulate information to its members from pharmaceutical and other commercial healthcare companies. The Committee endorses the ABPI Code of Practice and Department of Health Ethical Standards on commercial sponsorship. The committee have decided that information on individual products will not be circulated to members as it is their view that this is the responsibility of company reps. This includes updates on drugs. An exception may be made for circulation of information where no one company is favoured above another.

Nurse Audit Tool - criMSon

Hüseyin's blood pressure has come down now that the Nurse Audit Tool has been finally completed with all bugs out of the system. A CD-ROM of the Audit Tool has been sent to all members and we hope that you will find it useful.

Remember that you can change the questions to suit your own work situation.

About forty CD-ROMs were sent out in July and these do have a bug in the program which affects the reports in the Word document and Powerpoint presentation. It does not affect the audit itself. If you received your CD-ROM earlier in the Summer (the revised version 2 was posted in September) and want to have an updated version, please contact Mary Fielding.

If you have any questions about using the Audit Tool, please contact Hüseyin or a member of the Steering Group.

MS Nurse Exam



Fifteen people will be sitting the MS Nurse International Certification Examination in November, almost double the number who took it last year.

There will soon be a webpage devoted to the MS Nurse Exam, where you can find more information.

Around seventy MS Nurses in the UK have now successfully taken the exam – why not join them? The Committee agreed at their September meeting that UKMSSNA members would once again be supported with their contribution to the exam fee being met by the UKMSSNA. We are extremely grateful to the IOMSN for providing bursaries to cover most of the \$250 fee.

Psst Password reminder!

If you can't work out your password to get into the Members Section, just look for the box at the top of each page which says "Forgotten your password?" and it will tell you how it works.

Website



We hope you have noticed some changes to the Members pages of the website over the past couple of months – there are now new pages for each Region, including a "Google" map which shows (roughly!) where UKMSSNA members are based and a list with their contact details, as well as any information provided by the regions about meetings, work in progress, etc. There is also a page for Associate Members which has brief biographies of our Associates and their special interest in MS.

Two new and significant changes will be made in the course of the next few months.

The first is a "Search" facility to find members' details and the area they cover more easily. The Search tool is based on a database and to work effectively the information must be specific.

To do this we need your help. Please complete and return the enclosed form following the instructions carefully.

The second change is that instead of having sections for the Care Plan, Slide Library, Protocols, etc., there will be a separate page for each MS issue and that will contain all the information we have on that issue. So, a page on "Bladder and Bowel" will include any Care pathways or Protocols, any members' queries, the "Bladder and Bowel" section of the Care Plan, Slide Library presentation and the same for each symptom, treatment or any other MS information. We hope that that will make it easier for you to find information quickly. This will take time, though, as there is a lot of information to shift around and there's only little me (and ever-so-useful partner David) to do it!

I also intend changing the look of the website to include more pictures and graphics. Again, I'm on a learning curve here, so don't expect miraculous changes

soon. Any photographs or other images you can send me (with appropriate permissions) will help enormously.

Mary Fielding

Membership Matters

We hope that being a member of the UKMSSNA is valuable to you. If you think it is, please encourage any colleagues who are not yet members to join us (they can download an application form from the "Joining" page of the website). If you don't think it's good value – tell us why!!

By the way, talking about Membership and downloading forms, you can also print off:

- copies of the Membership Renewal form (in case you've lost the one sent to you when your subs. are due)
- the Standing Order form (much the easiest way to pay)
- a **new form** which you can use to let us know about changes in contact details or changes in your circumstances, e.g. if you are on maternity/paternity/adoption leave or on long term sick leave.

All these are on the "Joining" page of the website.



Multiple Sclerosis Society

Change of role for Sheila Manley

After 20 months, Sheila Manley is changing her focus and is taking forward Palliative Care as a new National Programme for the MS Society. Whilst Sheila has really enjoyed her time as Specialist Nurse and Practitioner Fund Manager and has made positive changes to the Fund, she has decided to work part time and concentrate on palliative and end of life care aspects which until now have been a small part of her role. The Society will be working very closely with the National Council for Palliative Care and, following a four nation workshop in October, will be developing this work. A Professional Network conference will take place in June 2009 in Newcastle on this theme. Sheila's contribution to the

Specialist Nurse and Practitioner Fund has been considerable and the Society is fortunate that it will not lose her expertise and knowledge as she takes forward her new role.

MS Society Library on the internet: a new way to find information 24/7

For years the MS Society has had a library to support the information needs of people affected by MS, but no facility for people to search it themselves and access the documents. Now, a new database opens up the library for anyone with access to the internet to see what's available, download documents and request loans.

What's in the library database?

- **The full text of MS Society publications** including all of the Essentials series and many articles from MS Matters from the last 4 years. Simply find the record, click the link and read the document.
- **Web links** to key publications and articles on MS produced by other organisations
- **A shopping cart** facility – find and request loans of books, DVDs and CDs, by email. (Requests for articles not published by the MS Society must still be made by post with a signed copyright declaration and payment.)
- **Easily identifiable information for a lay audience or for younger people** – the library includes a wide range of information on MS: from highly scientific material through to information for people affected by MS. Just add the terms "lay" or "children" in the Primary Audience search box to find the appropriate information.
- **DOI links to professional journals** – this means that if your institution subscribes to the relevant journal, or the article is 'open access', the links we provide will take you straight to the full article. If not, you will still usually be able to access the abstract.

This resource is available 24/7 at: <http://mssociety.soutron.com/InmagicGenie/opac.aspx>

If you don't have access to the internet, you can still call or write to the information team who will search for the item you're after.

The Information Centre is still open to visitors.

For further information contact David Bates, 020-8438 0900, librarian@mssociety.org.uk

Date for your 2009 diary

The next MS Life event will take place from 12-14 June 2009 at the Sage Gateshead. Watch the MS Society website for details.

information
education
research and
support



In the coming quarter there will be a number of new items from the MS Trust of direct relevance to members of the UKMSSNA:

1. **MS Explained** has, since its first version in 2005, been a trusted publication to explain to people with MS, their friends or families, what is happening within the nervous system. A new edition will be launched at the MS Trust conference. The book has been revised in light of recent advances and includes a new section on future avenues of research.
2. **Tips for Living with MS** a publication produced by collecting tips from people with MS about how to live with MS has been available since 2002 and remains one of the Trust's most requested publications. An updated reprint will be available in November.
3. **MS commissioning pathway**
Research has shown clearly that the understanding of MS is low within primary care and thus the commissioning of MS services is fragmented. The MS Trust has funded the development of an MS commissioning pathway, working closely with the ABN, RCP, RCN, commissioners, the MS Society, people with MS and the UKMSSNA. The Trust is especially grateful to Nikki

Embrey who was one of three original authors, the other two being Dr Peter Brex and Vicki Matthews. The pathway will be launched later this month.

Finally, at the MS Trust conference Prof. Clare Fowler will be launching an **MS Bladder consensus statement**. The MS Trust has facilitated the production of this statement. Many people with MS have bladder problems and it is hoped that this consensus statement will provide guidance to commissioners, health professionals and to people with MS about how the bladder should be managed from diagnosis through varying levels of disability. If you are not going to be at the conference watch the MS Trust website for details.

Trust and Society success at the BMA Patient Information Awards



The MS Trust has always worked closely with health professionals and recently two publications conceived out of joint working between the Trust and MS specialists were recognised at the British Medical Association (BMA) Patient Information Awards.

Sexuality and MS: a guide for women was awarded first prize for Patient Information - Women's Health. In addition *Move it for MS!* received a Highly Commended at the ceremony held in London on 9th September. Nicki Ward-Abel and Liz Betts were at the ceremony to join in the celebrations.

In addition, two of the MS Society's publications were honoured. *Annie and Dan talk about MS* and *MS Essentials 26: Balance and MS* were both Highly Commended for their quality of presentation, content and clarity of message.

Congratulations to all involved.

Wales, Northern Ireland & Scotland

We have a tendency to concentrate on what's happening in England – but we shouldn't forget that Wales, Scotland and Northern Ireland have a different NHS set up. Aware of this, the UKMSSNA Committee heard about MS Nurse services in the other countries of the UK at their September meeting.

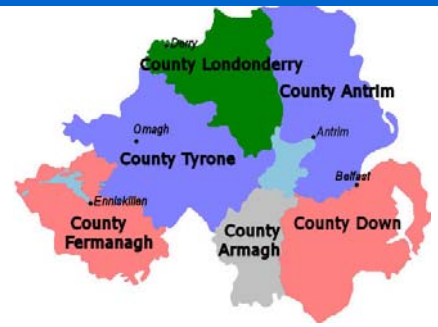
Wales – South Wales is very well served with MS Nurses and The Walton Centre provides MS Nurse support to patients in North Wales, but no-one has taken ownership of mid-Wales, which is currently served by Del Thomas in Herefordshire and Kate Watkiss and Denise Cooper in Shropshire as best they can. Health Commission Wales published a report which recommended a managed clinical network for mid- and South Wales. Welsh Health Boards are going to have to increase their provision. Powys has been offered service by Herefordshire and Shropshire PCTs if Powys will fund it, but they have refused so far. This area desperately needs an MS Nurse. Neuro contact will still have to be made through England for the foreseeable future according to the report. North Wales wants to provide independent services - clinics are currently provided by neurologists and MS nurse at The Walton Centre.



Del Thomas

Northern Ireland: Health and Social Services are integrated and always have been. Belfast can directly refer to a local service, e.g. physiotherapy. MDTs work together and know each other. There are 11 neurologists, 4 of whom have special interest in MS. 4 f/t MS nurses and 2 p/t in Belfast, 1 + others in other Boards. This

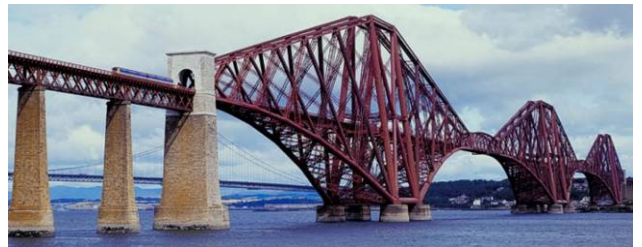
makes it easier for patients as referrals are made to services provided locally.



NI has its own Health Minister who knows the local situation and has been lobbied by local MS Society. For instance, the Minister went out with ambulance crews over a weekend to see abuses – drinking, etc. Also responsible for Social Services and public safety. Everyone works together and patients get a really good holistic service, but don't always realise this. NI is divided into four Boards who plan policy, legislation and set targets. In April 2009 the Boards will be abolished and one will be set up with five Trusts – Belfast, Northern, Southern, Eastern and Western - which will have commissioners who will be responsible for day to day running of the service. Patients who are seen privately don't have the same access to an MS nurse as those who are seen through the NHS as MS Nurses do not attend these clinics which are held in purpose built buildings. If a patient misses an appointment or has not been seen for a long time they will drop out of the system. 1550 phone calls for advice/help in a year. Audits of new services. There will be no prescription charges from April 2010.

Iris Hume

Scotland:



A lot of parallels with NI. Devolution in 2000. Mainly SNP-led now with a Minister for Health and Well-being. Health and Social services are still split but trying to bring them together. Report – Delivering care; enabling health. MSS Scotland has a very strong voice. There is an MS specialist nurse in each of 14 Health Boards in Scotland funded centrally and

centrally commissioned, but there are local commissioners as well. Don't have acute and primary care boundaries in some Health Board areas – management is now by one person so the patient journey is now much smoother. There is more contact with patients and colleagues in the community – Most MSSNs are not stuck in acute or primary/community care. MSS Scotland has a very strong voice and has put funding into posts in each of the Health Boards. Neurological organisations formed a Neurological Alliance for Scotland in 2004 which is being listened to by Scottish Government. In May 2006 the Long Term Conditions Association was set up which held a conference in November 2006 “Gaun Yersel!” (trans. From Glaswegian; “Go on, Yourself!” or “Go For It!”) which put forward recommendations (see conference report at http://www.ltcas.org.uk/fileadmin/ltcas/images/_notes/ltcas_report_080107_final.pdf). This has been taken up at Scottish Government level. In Ayrshire, Alan's area, they are revamping services undertaking a commissioning exercise on neurology provision, including 2 new Neurologist posts, split half in Glasgow and half in Ayrshire.

Alan Izat

I did audit all my patients a while back. One of the questions was “do you know who your MS Nurse is?” One reply came back; “I don't know who my MS Nurse is but if I have a problem I just ring John.”...Bless. So I might need to do more work on job titles but at least she knows where to ring!

John Pohorely

From Print to Electronic

Printing and posting this newsletter is a significant cost to the UKMSSNA and is funded entirely from our own limited resources. As virtually everyone is on e-mail now, the committee have decided to change to an e-newsletter which Mary will send to you every two months. This will have the added benefit of keeping you up-to-date with forthcoming events, news and queries from members.

If you don't get any e-mails from Mary it could be because your NHS provider blocks receipt of any e-mails that look like spam. Check with your IT department. A few members have not provided us with an e-mail address and some others have not given us permission to include them on the e-mail distribution list. Contact Mary (admin@ukmssna.org.uk) if you want to check your e-mail status and join the Distribution List.

Thank you!

Thanks to everyone who responds to e-mail requests for information. We get a fantastic response to most queries, especially when a nurse is having a particular problem with an individual patient. I really appreciate that you take the time to reply and I know that the nurses who ask the questions are grateful too.

UKMSSNA Bursary to attend MS Trust conference

We had four nominations for the bursary and the successful applicant was nominated by Sandie Constant. Elizabeth Smith works in a Sue Ryder Home and is the link professional for people with MS. She says, “I am interested in all topics covered by the conference, especially those difficult symptoms associated with severe disease, conventional and alternative approaches.

Making a Difference 2008

Who are you going to nominate as the MS Nurse who has made a significant contribution to MS Nursing in 2008? Nomination forms will be available at the Conference in November for award next March at the York meeting.

See you in Leeds?

If you're going to the MS Trust Conference, do come and say Hello. It's nice to put a face to a name – even if “senior moments” mean I put the wrong name to the face!

The UKMSSNA will have a stand and will also be in the Information Zone on Monday afternoon.

Mary