



multiple sclerosis
specialist nurse association

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UKMSSNA: New Committee

Welcome to our 2nd newsletter - there seemed so much to tell you that this seemed the best way of imparting it all.

The elections have now been completed and your new committee is looking forward to consolidating the role of the UKMSSNA. Forty-eight responses were received at the correct address and in time. There were 11 spoiled papers - 4 were too late and 7 went to the wrong address. We thank the members who have 'retired'. Without the vision, commitment, foresight and clinical expertise of Bernie Porter, the

first chair of the UKMSSNA and first Consultant Nurse in MS, the organisation would not have had as high a profile as it does. Other members of the committee who have now 'retired' are Gail Clayton (but we have co-opted her for projects), Nikki Embrey (still much involved with the RCN) and Anne McCaffrey. All were very active and we are sure to use their expertise along the way. Some of the documents that were collaboratively worked on by the UKMSSNA, MS Trust and

RCN are now being used as templates for other specialist nurse groups.

Nicki Ward also 'retired' but has been co-opted for her clinical / educational expertise and her political awareness.

As regional representation of the committee was voted in at our AGM in November last year, you may now have someone near you. Below are the names, contact numbers and areas that all committee members represent.

If you have changed your job, place of work or contact number, please let Sarah know to update your details.

As you are aware, the UKMSSNA has made great efforts to be regionally representative. If you are currently not in a regional MS Nurse support group and would like to find out where your nearest one meets etc, please contact your nearest committee member and ask for details or register your unmet need. There may be others in your area interested in setting up such a group.

Name	Area	Contact number / e-mail
Nicki Ward (co-opted) (Co-chair)	West Midlands	0121 331 6177 nicki.ward@uce.ac.uk
Gail Hayes (Co-Chair)	South West England	01392 208 588 gail.hayes@rdehc-tr.swest.nhs.uk
Rhona MacLean	North East England	0113 206 4692 rhona@maclean57.fsnet.co.uk
Heidi Thompson	Northern Ireland	02890 635 261 heidi.thompson@royalhospitals.n-i.nhs.uk
Judy Percy	Outer London	01189 636 369
Kerry Mutch	North West England	0151 529 5645 kerry.mutch@thewaltoncentre.nhs.uk
Nicola MacLeod	Scotland	01224 551 263 nicola.macleod@arh.grampian.scot.nhs.uk
Pauline Shaw	Inner London	020 7771 3317 pauline.shaw@southwarkpct.nhs.uk
Rhiannon Jones	Wales	02920 745 018 rhiannon.jones@cardiffandvale.wales.nhs.uk
Sylvia Hurst	Kent	01634 825 003 sylvia.hurst@blueyonder.co.uk
Victoria Gutteridge	Southern England	023 8079 6864 victoria.gutteridge@suht.swest.nhs.uk
Diane Watts	Sheffield	0114 271 2302 diane.watts@sth.nhs.uk
Main address for honorary secretary and treasurer:- UKMSSNA, Spirella Building, Bridge Road, Letchworth, Hertfordshire, SG6 4ET Tel: 01462 476702 sarah.crombie@mstrust.org.uk or val.quieros@mstrust.org.uk		

The British Journal of Nursing Awards 2004

The UKMSSNA would like to congratulate 2 of its members who won a free place at the BJN Award Ceremony at the Savoy Hotel, London on Friday 21st May 2004. As you are aware, the UKMSSNA offered this prize for the 2 best entries discussing evidenced based practice in MS care.

The two nurses who won were Pauline Shaw, MS Nurse Specialist of Southwark PCT who wrote about a workshop she has designed for pregnant women who have MS, and Sharon Grainger, Neurology Nurse Specialist at Coombe Park in Bath who produced a reflective piece exploring the causes and assessment of psychological dysfunction in the patient with Multiple Sclerosis. This prize was sponsored by SeroPharmaceuticals.

The advantages of being a member of the UKMSSNA are various and ever-growing and include:

- Being a member of a specialist organisation. The UKMSSNA act as a voice for UK MS specialist nurses and allied professionals, where a strategic view or perspective is required.
- The UKMSSNA aim to act as a national resource and network for nurses and allied professionals to share their knowledge, expertise and best practice about MS and its management.
- Opportunity of volunteering to join specialist sub-committees or projects, all of which will develop clinical nursing practice. The slide library is already underway and includes 3 UKMSSNA board members and 4 national members. Please refer to the enclosed letter. This is a really exciting project which will benefit all members and will be provided free of charge to them. We are also asking for volunteers for another innovative project, the Research and Development Group, see later in this newsletter for details.
- Reduced rates for our own study days. We have had 2 to date, the last one was in Birmingham and was enjoyed by all who attended.
- Receiving a free copy of the United Kingdom MS Care Plan (£100 for anyone else)
- Affiliation with the International Organisation of MS Nurses (IOMSN)
- Small annual fee, for which you can claim tax relief
- Reduced fee for sitting the MS Certified Nurse examination

..... So encourage some of your work colleagues to become members also. Details can be obtained from Sarah at the MS Trust.

BSc Clinical Nursing Studies Degree in Palliative Care achieving a specialist practitioner award in Multiple Sclerosis

The University of Central England (UCE) in Birmingham has developed a new degree aimed at nursing staff caring for people with palliative care needs. It is an innovative course where students will study palliative care in general, as well as examining MS care in a specialised way. On successful completion of this course the student will obtain a palliative care degree as well as a specialist practitioner award. The degree is undertaken over 2 years and students enrolled will be required to attend the university for one day per week.

The 3 Level 6 MS modules that have always run at the UCE; Assessment and Diagnosis of MS, Therapeutic interventions in MS and Psychosocial Perspectives in MS will continue to be provided. Each module is now offered on a week block basis at a cost of £155 per module. They are offered either at an academic level when students are required to complete an assignment, or on an attend only basis where no assignment is required. The dates for those wishing to attend the next module, Therapeutic Interventions in MS are 11/10/04 - 15/10/04. Currently there are still places available if anyone is interested in enrolling for this module.

For further information about either of these educational opportunities, please contact Nicki Ward on nicki.ward@uce.ac.uk or 0121 331 6177.

A Fatigue Management Programme in MS - An evidenced based multi disciplinary approach to managing fatigue with people who have MS

This Fatigue Management Programme is a comprehensive training manual designed to provide healthcare professionals with the information and skills necessary to organise and run a fatigue management course for people with multiple sclerosis. There are 6 sections in all within the manual, including the results of a small piece of research that was undertaken to establish whether this programme was effective and whether any benefits that were perceived carried over any significant length of time. All the resources needed to run a fatigue management programme are included.

If you would like to reserve a copy of the Fatigue Management Pack, please email jean.legg@uhb.nhs.uk. The pack will be available in the printed version at £35 and CD Rom at £20.

The MDT at University Hospital, Birmingham who established this fatigue project would also like to invite other interested individuals/teams to take part in a national research project investigating on a larger basis whether fatigue management programmes such as this are effective for people with MS. They have organised a study day at the Postgraduate Centre at the University Hospital, Birmingham on Wednesday 8th September 2004 to discuss this further. A variety of talks/workshops on fatigue will be provided and then people will be asked whether they would like to participate in this exciting project. If you would like to hear more about this project or would like to take part, please email Catherine Sykes, Deputy Head of Occupational Services on: catherine.sykes@uhb.nhs.uk

International Certification Exam for MS Nurses

Many people involved in the field of multiple sclerosis believe that the knowledge, skills, experience and competence levels required to practice as an MS Nurse deserve formal recognition to distinguish MS nursing as a unique speciality. As a result of this, a panel of International Clinical Nurse Specialists in MS have formulated a certification examination, which is both psychometrically sound and legally defensible and which on successful completion will form a highly valued and formal recognition of MS nurses knowledge. This certification is recognised for 5 years, at the end of this time period, nurses are asked to apply for re-certification. This is achieved by a variety of ways and does not necessarily mean you have to re-sit the exam.

As many of you maybe aware the examination comprises of 150 multiple choice questions for which the pass mark is approximately 110 correct answers.

To date over 150 nurses internationally have successfully passed the exam, British nurses have done well and their marks, on average, are only second to the Canadian nurses.

The next sitting of the exam is on Sunday 7th November 2004 at the MS Trust's Annual Conference in Harrogate. It will take place from 11.00-13.30. If you would like to find out anything else about the exam, please email nicki.ward@uce.ac.uk. If you would like further details of the application procedure, please email: sarah.crombie@mstrust.org.uk and she will send you a registration pack. There is a deadline for submission of applications; no later than **FRIDAY 27th AUGUST 2004**.

Research and Development Working Group

Many of you will remember at the UKMSSNA AGM in November 2003, a motion was proposed and seconded that a research and development working group composed of UKMSSNA members should be established. This group would be accountable and report back to the UKMSSNA committee. It is hoped that the group will act as a focus for developing nurse led research. We would now like to move on this and would therefore request that any members who are interested in this innovative venture should contact Nicki Ward or Gail Hayes in the first in-

Agenda for Change Audit

Thank you to all those of you who attended the MS Trust Specialist Course at Oxford who completed the agenda for change audit. For those members who didn't complete the audit, can you please complete the enclosed form and return it to Bernie Porter, Consultant Nurse in MS, National Hospital for Neurology and Neurosurgery, Queens Square, London. Bernie, as a parting gift to the committee, is collating this piece of work. We hope that it will enable all nurses to be on the mailing lists appropriate to their practise.

We are really pleased to include the following 2 sections – keeping up to date with all that is going on is so important as is having advance note of any education days or new materials.

News from the MS Society

Primary progressive MS

Saturday, 11th September is the date of an MS Society Information Day for people affected by primary progressive MS. The event will take place in Birmingham running from 11 – 4 pm. Speakers will cover current research and future directions in primary progressive MS; health and sexuality, healthy bladder and bowel, mobility and seating problems. If any of your patients, their family or friends would like to attend, they can obtain further information or book a place by ringing Paul Crossman on 020 8438 0809 or e-mail pcrossman@mssociety.org.uk. Paul is also able to send you a poster for display in clinics if you contact him.

New to the Society's website is a dedicated message board for people affected by primary progressive MS where your patients can share experiences and chat to others. To log on, go to www.mssociety.org.uk/ppms.html

New professional training video

Caring for people with MS in the community is a new professional training video for staff who provide care for people with MS in care homes, in domiciliary care and in primary care. The video features interviews with a wide range of MS specialists and people living with MS. The video will be available shortly. To order your copy, please e-mail education@mssociety.org.uk giving your UKMSSNA membership number.

Affiliation to the IOMSN

Those of you who are full members of the UKMSSNA have the option to become affiliated members of the International Organisation of MS Nurses (IOMSN). We are aware that not all full members have taken advantage of this. As the UKMSSNA and IOMSN are separate associations, we need your signed permission to pass your contact details on to the IOMSN due to the Data Protection Act, before you become an affiliated member. All full members are sent a form on joining the UKMSSNA to sign and return to the UKMSSNA secretary, who will then pass on your contact details to the IOMSN. If you are a full member and you haven't returned this form, or haven't received any information from the IOMSN, then please contact Sarah who will be able to forward you the appropriate details; Tel: 01642 476702 or E-Mail: ukmssna@mstrust.org.uk

'Making a Difference' Award

The first committee of the UKMSSNA decided to award a prize for 'Making a difference'. The first such award was presented to Judy Percy who is working in Reading until June. Judy has been in post for over 5 years and was involved with Jane Johnson's seminal work on describing the role of an MS Nurse. Judy is resourceful, an inspiration to others, so knowledgeable in her field, a good friend, mentor, and overall a great example of Multiple Sclerosis Nursing. Her work includes contact and support for all who live with MS – patients, carers and families. The 6 roles of being a specialist nurse have all been exercised. We wish Judy a long and happy retirement and know that her offer to help the new committee will not go unappreciated.

Helping you explain MS

Many of you will have heard about *Helping you explain MS: a teaching resource for health care professionals*. Sometimes described as the "teaching aid", these materials were produced by the MS Society in collaboration with the UKMSSNA and ABN. One copy of the pack is available free of charge to UKMSSNA members. Conceived and largely written by Bernie Porter, the pack contains colour and black and white illustrations of the biology of MS together with a CD Rom. It is designed to be used by specialist nurses, neurologists and other professionals in one-to-one teaching sessions with people who want to know more about the basic biology of their condition. There is limited availability of this resource. For your copy, please send your full details, confirming that you are a member of UKMSSNA (giving your membership number), to education@mssociety.org.uk

Getting to Grips with MS

The society has just published *Getting to Grips with MS*, guidelines for branches and regions on how to work with healthcare professionals in running courses for newly diagnosed people. The guidelines include sample course objectives and programme outlines, advice for facilitators, sample publicity materials, sample letters to participants and model evaluation forms. Most MS Society branches should have copies by now. If you would like a copy, please e-mail education@mssociety.org.uk If you have any general queries on the above, please e-mail Lynda Finn on lfinn@mssociety.org.uk or ring 020 8438 0808

News from the MS Trust

The Learning Needs Assessment Tool: for nurses working in MS

May saw the launch of the Learning Needs Assessment Tool (LNA tool). The purpose of the tool is to help identify areas of your professional practice which may need further development. It has been designed to help you consider a number of questions which will help you to develop your clinical and professional practice. These questions are:

- Where am I now?
- What are my learning needs?
- How, where and with whom do I learn?
- How can I meet my learning needs?
- What do I do next?

The tool is organised in sections which address each of these questions in turn. In each section you will be presented with different exercises to help you profile your learning needs. The exercises include:

- Mapping your current role
- Identifying the priorities for your service
- Caseload profiling
- Learning needs analysis
- Developing a learning profile.

This is an excellent tool and will help you develop clinically and professionally.

It was decided that the best way to launch the LNA Tool was by training several key nurses so they are equipped to train their local colleagues. This initial training was completed at the beginning of April. The steering committee/trainers are listed below:

- | | |
|-------------------|------------|
| • Sam Colhoun | Birmingham |
| • Gail Hayes | Exeter |
| • Liz Keenan | London |
| • Fiona Lynch | Liverpool |
| • Viv Oliphant | Edinburgh |
| • Andrew Russell | York |
| • Pauline Shaw | London |
| • Jacqueline Smee | Cardiff |
| • Heidi Thompson | Belfast |

The local trainers will be discussing the best way of organising the local training and will be accessing the relevant files for you from the MS Trust.

We all hope you will find the Tool beneficial and look forward to any feedback you may have.

MS Trust Eighth Annual Conference 2004

The conference will be running from Sunday 7th to Tuesday 9th November, and will be at the Majestic Hotel, Harrogate. A flyer should be on its way to you soon in order for you to register your interest in the conference, and a full conference programme will soon be available to view on the MS Trust website.

Speakers already confirmed include;

Prof Alan Thompson, Dr Diane Playford, Elaine Cooper, Prof George Castledine, Candy Cooley, Lynda Hind, Dr Eli Silber, Dr Carolyn Young, Sally Wilson, and Prof Pam Enderby to name but a few!

For a registration pack and further details, please contact the conference secretariat:

Packer Forbes Communications, 53 Cavendish Road, London, SW12 0BL Tel: 020 8772 1551 Fax: 020 8772 1552

E-Mail: MS2004@packerforbes.com

New publications from the MS Trust

Those of you who attended the MS Trust's specialist course in Oxford will know that we launched two new publications: 'MS Explained' and 'Exercises for people with MS'.

'MS Explained' provides a straightforward explanation aimed at anyone who wants to understand what MS does to the body. It purposely avoids discussing the treatment and management of symptoms, which are covered by other publications and factsheets.

The intention of the book is to provide a dispassionate and easily accessible guide to what MS is, how it affects the immune system and the central nervous system.

Fatigue chatroom

The next expert chatroom will be on fatigue and will take place on Thursday 10th June between 10am and 7pm. Experts online during the day will include Sarah Broughton and Carole Shaw, both occupational therapists, and Val Box, who is a trainer on the Expert Patient Programme and has long personal experience of living with fatigue.

If you or any of the people you see would like an email reminder a few days before the session, please contact Simon at simon.webster@mstrust.org.uk. If people don't have access to the internet or won't be able to join the session on that day, they can still ask a question of the experts by sending it in advance.

A transcript of the whole session will be added to the archive of previous sessions available on the website a few days after the event. To order the transcript in hard copy, ring 01462 476700. For more information, keep an eye on www.mstrust.org.uk/chat

'Exercises for people with MS' has been written by Liz Betts, a physiotherapist from Suffolk. The concept of the book was to show what people with MS can do to help themselves. The book comprises of a programme of exercises, including illustrations, to help show how to prevent problems before they develop, alleviate some symptoms and to improve general sense of well-being. There are also useful sections on spasm, fatigue and pain.

Please contact us to request copies of the above: info@mstrust.org.uk