

Committee News

The new committee members have now been in post for nearly a year and it has been a very busy time for all.

Following a decision at AGM 2003, the UKMSSNA continues to strive for regional representation and also to have a third of the committee standing down each year. You will have received an invitation to nominate people for some areas. In this newsletter, the committee would like to thank those members who are standing down:

Rhona MacLean has been involved in MS Nursing for many years (when she was one of just 20 MS nurses) and

was involved in the initial meetings to define what an MS Nurse is and does!! Her expertise, passion and input for this role have been evident in all the publications, through the Steering Group and the Committee of the UKMSSNA. She 'retires' to continue her work writing a Distance Learning Masters course in MS for Leeds Metropolitan and practise in Leeds.

Heidi Thompson, from across the water in Northern Ireland, became involved in 2000 working on the Pharmaceutical Guidelines, Key Elements and Competencies documents with Rhona and others and also stands down. Heidi has many colleagues in Northern Ireland

and she will be missed for her enthusiasm and we hope that someone else will take on this role.

Judy Percy was presented with the first 'Making a Difference' Award last year and has now retired from the NHS and therefore from the Committee. However, we have all benefited from her wisdom in the past year. She is very active on the Slide Library sub-committee and we hope to continue with her support as a co-opted member.



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
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

We are sorry to have lost Sarah Crombie as our honorary secretary and hope to appoint a secretary to the UKMSSNA soon. The Committee thanks all at the MS Trust who have been and are aiding us in the interim.

UKMSSNA presence at meetings

We try and raise the profile of the UKMSSNA at every opportunity offered us. In October 2004, we were pleased to have a table and stand at the MS Society Convention in Warwick. Three nurses were around to listen and talk to the delegates who live with MS who came from all over the UK. We also had a stand at the MS Trust Annual conference and were extremely busy talking to the professional delegates. Our banner was on display and 6 new members were recruited.

Thanks go to both the Society and Trust.

N.B. Are any of you going to the MS Society Research conference to be held in Scotland? If so, please consider being on the UKMSSNA stand.

SROPS and BYLAWS

At a recent committee meeting we amended the SROPS and BYLAWS. Anyone wanting a copy of these will soon be able to download them from the website.

Members interests (professional!)

It has been suggested we hold a register of any Members with special interests (e.g most of us are aware of Nicki's special interest in sex) and this would provide a valuable resource for Study days etc. Please contact any of the committee members if you have a special interest.

DATES FOR YOUR DIARY

MS Trust meeting for MS Specialist Nurses 16th - 17th March 2005 (Oxford).

UKMSSNA Study Day 4th May 2005 (Warrington) This will be our 3rd annual study day looking at the wider picture of Nursing in the UK. A flier will be sent soon – book your flights, arrange your trains early to take advantage of cheaper travel! It will be open to all Specialist Nurses so we hope you and your colleagues will attend.

The British Journal of Nursing awards are on 20th May 2005 and take place at the Savoy. Closing dates for entries is early April. Our roles are so varied as are our areas of expertise, so get writing!!

The next opportunity to take the MSCN exam will be at the MS Trust Conference 13th -15th November 2005.

MS and the family

One of our committee members, Kerry Mutch, presented a well-attended session at the MS Trust meeting in Oxford last year and her work with families has now gathered pace.

MS has many hidden barriers that affect daily life such as loss of self-confidence, psychological, economic and social exclusion. Professionals tend to give the majority of information, support and care to the person with MS. However this does not address the worries and concerns within the family unit, as MS affects the whole family and not just the person with the diagnosis. Due to the uncertainty of what will happen in the future, children are not often asked what their fears, concerns or worries are and how MS affects them. Parents often don't want to worry the children. They don't believe MS affects them so they don't talk about it or they try to hide the disease to make everything normal. Hence, an 'MS in the Family' workshop was created - a day for young people (9-14) who have parents with MS.

The aim of the day was to:

- give information regarding MS in a practical interactive way
- meet other young people in similar situations
- identify others to share your worries with
- to enjoy the day and have some fun

The day consisted of giving factual information regarding multiple sclerosis, practical simulations of some of the sensory, physical, memory and visual problems to give the young people some understanding of the condition. The afternoon covered emotional aspects of living with MS and identified feeling, thoughts and concerns on how their lives are affected.

In conjunction with Joanne Ridley of the MS Society there is now a facilitator pack available to enable other MS nurses to plan a similar day in their area and also a workbook for the young people attending the day. Contact Jo

News from the MS Society

Helping you explain MS

Most members of the UKMSSNA have now received their copy of this teaching resource. If you have not received yours, just email education@mssociety.org.uk

PROFESSIONAL NETWORK

MS Network is the MS Society's new newsletter for professionals that will be published three times a year. If you have not received a copy, just email msnetwork@mssociety.org.uk. If you are not sure whether you are a member of the professional network just e-mail and we will send you an application form if you are not already on the list.

Conference

The 2005 professional network conference will take place in Bristol on 7th July. The theme will be the NSF and the conference will include comprehensive coverage, challenges and opportunities to implementation. Email cbray@mssociety.org.uk to book your place.

WEBSITE

The professional pages of the Society's website have been rewritten and updated and now include a new section for primary care professionals. Check it out on www.mssociety.org.uk. The website also has new pages on welfare benefits.

LIVING WITH MS DAYS

In 2005, there will be six 'Living with MS' information days for people with MS, friends and family. Each day covers the facts of MS, physiotherapy, coping with cognitive and continence problems and support for carers. Check the events pages of the Society's website for more details.

CARERS PROGRAMME

Recent additions to the Society's Carers Programme publications are Kerry and Jo's work and, aimed at teenagers, www.youngcarers.net is a new website published by the Princess Royal Trust for Carers (PRTC) including pages focusing specifically on MS. To support this new initiative, PRTC and the MS Society have published a leaflet that explains basic facts about MS and promotes the site. For more information, email Joanna Ridley on jridley@mssociety.org.uk.

UKMSSNA Website

The UKMSSNA website is again up and running. It can only be used by members. To access the website go to www.mstrust.org.uk/ukmssna

You should already have the username and password but if you have forgotten them, please contact a committee member.

So far you will find the following information on the website:

- Minutes of committee meetings with links to committee members
- A list of committee members and their contact details
- Tips for Agenda for Change

News from the MS Trust

MS Trust Ninth Annual Conference 2005

The MS Trust Annual Conference will be running from Sunday 13th to Tuesday 15th November 2005 and further details will be announced at the MS Specialists meeting in Oxford in March. A flyer will be sent to you soon in order for you to register your interest in the conference and a full conference programme will be available on the MS Trust website in the not too distant future.

New publications from the MS Trust

Information for Health and Social Care Professionals

The MS Trust is delighted to launch a revised edition of Information for Health and Social Care Professionals. This book has been compiled with the help of professionals with the aim of improving the level of understanding of MS amongst those who work with, and care for, people who have the condition.

The intention is to:

- offer an overview of MS
- provide a resource for professionals who work with people with MS
- answer some of the questions about the management of MS and its symptoms
- offer directions for further information through references and bibliographies.

Disease modifying drug therapies: a general guide for people with MS

A new version of this guide is now available, revised with the help of MS specialist nurses in Staffordshire and London. It gives information on the four disease modifying drug therapies currently licensed for people with MS in the UK.

This edition is aimed at anyone with MS looking for information on the DMTs, and thus replaces our current booklet and factsheet. We expect it to be especially useful to MS specialist nurses discussing this issue with their patients.

Tips for living with MS

In the two and a half years since it was published, over 15,000 copies of Tips For Living With MS have been sent out, making it one of the MS Trust's most popular publications. But then, it is written by experts in the field – people with MS. The book compiles nearly 150 useful ideas sent in by people with MS. These include practical suggestions on managing different aspects of life such as saving time and energy, getting around, making the most of benefits, getting equipped and now there is a brand new section on work, rest and play as well. The contact details for useful organisations are also listed.

To order copies of any of these books, email: info@mstrust.org.uk, or ring: 01462 476700.

Cognition chatroom

The next expert website chatroom will be on cognition and will take place on Wednesday 13 April between 10am and 7pm on www.mstrust.org.uk/chat. Experts online during the day will include Dr Sandy Burnfield, retired psychiatrist with MS, Patrick Carroll, clinical specialist occupational therapist and Dr Dawn Langdon, clinical neuropsychologist. Problems with memory, concentration span, visuospatial awareness and mood are all aspects that can be discussed.