Letter from the Chair

Sue Oliver takes us on a rheumatological train of thought

As often happens in our busy lives, I am starting this letter on the train coming back from the BSR (British Society for Rheumatology) Annual Meeting in Liverpool.

At such a difficult time in health care, it was inspirational to see so many of you there and so many fantastic posters and presentations – we (you) are really making an impact and showing the value of nursing!

For those who couldn't or didn't attend the BSR, the steering committee was kept busy with presenting, manning the stand or posters and representing the forum on other affiliated organisations.

It's our job to make sure the presence of the RCN Rheumatology Forum is ever present! I have to say I was remarkably proud to be a member of a dynamic and successful committee, representing such a brilliant band of nurses.

Let's demonstrate your value to managers

In response to enquiries from members, particularly in relation to ensuring managers understand the work that we do and the challenges we face, the forum is currently collaborating with the British Health Professionals in Rheumatology (BHPR) and the Nurse Consultant Group in some work to try and understand exactly what services nurses are delivering and how we feel about what we are doing.

The aim is to produce a definitive document that should help those of us who really want to demonstrate to managers and commissioners exactly what is a reasonable workload and what we can deliver in all care settings – not just the specialist nurses, although the focus is on areas that managers are challenging in particular at the moment.

It may also help us identify nurses working in different settings whom we don't hear about so much but who still need our information/support and representation. So watch this space and do make sure you fill in your questionnaire when it arrives.

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Rheumatology Futures Project

You may have already received and completed a questionnaire on the Futures Project, another piece of work that we are undertaking. This amazing collaboration, chaired by Ailsa

CONTINUED ON PAGE TWO

EDITORS NOTE:

UPDATE ON THE FUTURES PROJECT

Survey news thus far.
Of 2,315 health care professionals who were contacted, the response rate was 24 per cent (said to be very good for this type of survey). The patients always do better – 2,450 were contacted and the response rate was 40 per cent.

Results will be published in September, following analysis and further qualitative work.
CONTINUED FROM PAGE ONE

Bosworth and myself, aims to support the needs of patients and show what we do well and also where there are problems in delivering the service.

The hope is that we might also be able to develop a commissioning toolkit on top of raising issues in Westminster and lobbying for services locally. This survey should have been completed by the time the newsletter goes to print so we will be sharing the results shortly.

We hope the results from these projects will benefit you – will help your work and your job be recognised and valued, and also set out clearly what is being delivered across the country.

These two projects will help inform performance management and activity pressures some of you are experiencing and we hope even influence banding and job descriptions/coding, payment by results and more!

Looking down the line

As part of the committee’s agenda for the next few years, we are keen to build strong collaborations with other nurses who we hope will be able to work with us to improve care, particularly practice nurses, ward nurses and other long term condition forums.

We also want to build our membership numbers as an increase in numbers enables the forum to be more effective and have more of a voice.

As you know, the RCN has been going through a difficult review and re-organisation process that is not over yet ... but so far it has been reassuring to see that the RCN now has a strategy that means forums are integral to the organisation and should in the future have a lot more power to influence and support members.

For forum chairs this means a lot more paperwork and a lot more forward thinking in the sense of making operational plans and costing every aspect of our activities!

What’s it all about?

Although not new for our forum, it does mean that the infrastructure and support should encourage a more efficient way of working at the RCN and – for you as a member – it should also bring benefits.

A greater emphasis on a strategic approach to workloads will enable greater communication/collaboration and a focus on ensuring value for your money.

We have made some excellent progress during the RCN review process and there is still a way to go, but I feel much more hopeful about what we might be able to achieve for you, our members, in the next year. This will include an improved, user friendly forum website with much more in the way of useful resources for you.

For the forum conference in 2009 we are planning to run two one-day meetings at RCN headquarters in London. One will be for novice or new rheumatology nurses and the other for advanced practice. This is a provisional plan and we are interested to hear your views about the success or otherwise of this proposal.

But first, Congress

As is normal for my constantly travelling life, I am finishing this letter in Bournemouth during RCN Congress – a very different sort of conference that really shows what as a collective body of nurses can do when they get together to look at policy and improving care for patients.

I never thought I would be as interested in this side of the RCN, but I really must say, having had to get more political and active in recent years, I really would recommend that you come along to Congress next year.

Congress is important to us all and, while I have been here, I have had an interview with the Chief Nursing Officer Chris Beasley and raised issues such as threats to nurse specialist roles, banding, service re-design and how to demonstrate the value of nursing.

I have also attended sessions on the Healthcare Commission and standards, and voted on resolutions and discussions in relation to a range of important issues such as whether we want to keep the Pay Review Body, organ donation and much more!

I also managed with other forum chairs to have some awful pictures taken to raise awareness of what forums do.

And finally ...

I just want to say that the forum needs your help – we are continually trying to build our membership links and make sure that everyone receives their newsletter so if you know of people not getting their copy, then encourage them to get in touch with RCN Direct and let them know. As the old saying goes, “We really need you”. We also hope to ask you to become involved in projects.

The summer is on the horizon and I hope by the time you get this we will all feel more positive about the future of care for those with rheumatological conditions – and that we will be able to deliver that care, perhaps in a different setting but still using our expertise.

Did you know you can read this newsletter online?

This and other forum newsletters are available on the RCN website even before they are mailed out to members.

So if you would like to be one of the first to read the next issue log on to MyRCN at www.rcn.org.uk/myrcn, or call RCN Direct on 0845 772 6100, to register your email address and opt in to our email services. You’ll then be sent an email with a link through to the newsletter each time it is published.

Help us reduce our carbon footprint and save some trees!
2007 Pfizer award winner focuses on fibromyalgia

I was fortunate and very grateful to have had the opportunity to attend the American College of Rheumatology annual conference in Boston last November.

The format was similar to previous conferences I have been to, such as the BSR and EULAR (European League Against Rheumatism), with scientific presentations, poster viewing, opportunities for networking and workshops.

However, the scale of the conference was more extensive, resulting in the usual dilemma – that is, with so much choice, how can I decide what to attend!

As my research interests are in sleep disorders, I opted for an agenda that was predominantly related to fibromyalgia, given that this complex chronic pain disorder is associated with sleep disturbance and its management is not uniform.

Spoiled for choice

Presentations were wide ranging including, for example, the language of pain among fibromyalgia patients, educational needs, effectiveness of exercise, employment status, principles of treatment and treatment programmes including alternative therapies.

Further presentations described the results from investigations using functional magnetic resonance imaging, which demonstrates a physiological explanation for fibromyalgia, and single photon emission computed tomography, which looks at regional cerebral blood flow and demonstrates changes in the brain function of people affected by fibromyalgia.

Pharmacological treatment and alternative therapies have an important role to play in the management of fibromyalgia. Data were presented relating to pregabalin, the first approved drug for fibromyalgia, and for the efficacy of a combination of norepinephrine and selective serotonin re-uptake inhibitors such as duloxetine. Consequently the use of these treatments has been incorporated into our evidence-based guidelines.

Not just drugs

As sleep disturbance is a significant problem for patients with fibromyalgia and in many other patients with rheumatic diseases, I was keen to hear any recommendations for improving it. Thus the presentation “Improving sleep – non pharmacological strategies” helped me ensure I was up to date with other health professionals.

There were sensible suggestions relating to assessing sleep quality and fatigue, sleep hygiene and cognitive behavioural therapy. I even enjoyed a brief doze when we were invited to close our eyes and actively relax.

However, I was somewhat alarmed when the presenter recommended sleep deprivation in order to develop a sleep debt and consolidate time spent asleep, particularly as this advice did not appear to be based upon any evidence.

When in Boston ...

The conference centre was huge and the programme extensive – however, having travelled to Boston, it would have been churlish not to visit the city centre. And with the favourable exchange rate I thought it would be verging on a crime not to shop! And so shop I did ...

In conclusion, I had a great opportunity to further my knowledge, consolidate my practice and visit a lovely city. All in all, it was a great trip which I can strongly recommend. So fingers crossed – I might get to San Francisco in October for the 72nd Annual Scientific meeting. Hope to see you there!
Our forum bursary winners had more in common than a last name – both had a great time at our annual conference this past January in Cardiff.

Two Wrights can’t be wrong!

From LYNNE WRIGHT
I was lucky enough to win a bursary to attend the conference and, never having won anything in my life before, I was really excited about it! My high expectations were definitely met when my smooth journey to Cardiff led me to the magnificent City Hall building, which was resplendent inside.

As it was my first conference, I was unsure of what to expect, but the atmosphere was buzzing and I soon got chatting to complete strangers as we perused the different stands and got bagsful of goodies for the girls at work before the Chair started her opening remarks.

The programme was stimulating with a fabulous range of speakers. I found the speakers from primary care very interesting as it’s a new perspective for me.

Up close and personal
After lunch on the first day, there were four concurrent workshops to choose from. We had a great session from Debbie D’Cruz whose workshop was entitled, “How to perform specific articular examination. The GALS screen.” This involved networking of the highest order when examining each others joints!

The hotel was lovely and, on a personal note, I managed to sleep throughout the night without disturbance (I have a two year old!). The conference dinner was a great occasion and I met some fabulous people. It was definitely a situation where it was fun to "talk shop".

The second day saw a very interesting and thought-provoking discussion by a panel whose members are passionate about rheumatology care. For fun, the Chair, Sue Oliver, had an audience clap-ometer to gauge audience reaction!

The time seemed to fly by and when the conference ended, as well as coming away laden down with goodies, information, new contact numbers and new knowledge, I felt wonderfully invigorated.

I definitely recommend conference-going and certainly look forward to my next one.

Lynne Wright is a Rheumatology Sister at Derby Hospitals Foundation Trust.

And SARAH WRIGHT
The focus of this excellent conference was the patient’s health care journey in primary and secondary care.

Ailsa Bosworth, Chief Executive National Rheumatoid Arthritis Society (NRAS), gave a comprehensive presentation on the “Hidden cost of RA on the patient’s journey”. This covered patient’s personal costs including emotional and psychological distress, loss of employment and the impact on carers.

The financial implications of having RA were highlighted by a complex integrated care pathway which follows patients throughout their health care, impacting on further personal loss and wider costs to society.

Care in the community
Two practice nurses providing nurse-led support and monitoring of patients with inflammatory arthritis presented their community roles. Questions were raised about opportunities for more education in this area of chronic disease for practice nurses to pursue their role as they currently do in areas such as asthma and diabetes care. A community matron in Cornwall also explained how this service can support rheumatology patients.

I attended two workshops on performing an articular examination using the GALS screen, a tool used to detect musculoskeletal abnormalities, and the impact IT changes will have on rheumatology nurses working in hospitals.

A lively debate took place on how rheumatology services should be delivered in the future. Perspectives were given by a consultant rheumatologist, GP and an extended scope physiotherapist, all of which gave food for thought in the way we could deliver care.

Continuing care for end stage disease was presented by a consultant rheumatologist with a moving case history and reflection on some of the patients we all see in clinic. This is an area of care we are aiming to involve the palliative care team in at our hospital.

Sarah Wright is Rheumatology Nurse Practitioner at Poole Hospital NHS Foundation Trust.
Background

Rituximab is a selective B cell depleter that has been used for many years in lymphoma and is increasingly being used in rheumatoid arthritis. NICE has recently published a final appraisal determination on the use of Rituximab in rheumatoid arthritis stating that they recommend the use where at least one anti-TNF alpha treatment has failed. However, it also states that there are no published data comparing the outcome of Rituximab with anti-TNF alpha treatments. This report analyses data from St. Helens Hospital for the past two years on the efficacy and safety of Rituximab for refractory rheumatoid arthritis (RA), in cases where anti-TNF \( \alpha \) treatment has failed or is contra-indicated and compares with the patients who commenced anti-TNF therapy in the last year.

Methods

The patients involved were recruited from the rheumatology department at St. Helens Hospital. Ten patients treated with Rituximab between March 2005 and March 2007 were involved in the study. These were compared with 18 patients starting on anti-TNF\( \alpha \) between January 2006 and January 2007.

Rituximab was given in two infusions, two weeks apart. Patients were given 100mg methyl prednisolone intravenously 30 minutes before commencing Rituximab 1000mg infusion on day one and day 15. Some, but not all, patients had oral prednisolone between the two infusions (60mg daily for one week, 30 mg daily for one week).

The efficacy was assessed in both groups using DAS 28 scores before and after treatment. Any history of side effects including infections were recorded at time of infusions and at each clinic visit.

Results

Five patients treated with Rituximab had primary contra-indication to anti-TNF therapy (two bronchiectasis, two previous malignancy, one recurrent UTIs) and five patients had had previous anti-TNF therapy (two ineffective, one developed breast cancer, one primary thrombocytosis, one recurrent chest infections – bronchiectasis on HRCT).

The time between the start date of treatment and the post-treatment DAS 28 scores was on average 13 weeks in the Rituximab group and 13 weeks in the control group.

There was only one significant infusion reaction requiring the infusion to be discontinued. There were no cases of infection requiring antibiotics in the infusion group, with four in the anti-TNF group despite four of the Rituximab group having history of recurrent infection.

Conclusion

Rituximab was effective and well tolerated. The response was similar to that of anti-TNF therapy in a group of patients who had either failed anti-TNF or had contra-indication to therapy with anti-TNF. This study shows that in routine clinical practice Rituximab was as effective as anti-TNF therapy in patients who had failed or had contra-indication to anti-TNF therapy. The NICE guidelines are to be welcomed. However, they fail to cover the use of Rituximab in patients with rheumatoid arthritis in whom anti-TNF therapy is contra-indicated nor do they cover the possibility of use of Rituximab prior to anti-TNF therapy.

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Varicella-Zoster virus and the immuno-compromised patient

Chicken pox and shingles are both caused by the varicella-zoster (VZ) virus. The primary infection causes chicken pox, while reactivation causes shingles (herpes zoster).

Up to 90 per cent of the population will be exposed to VZ during childhood. The virus is spread through droplet, aerosol and direct contact, which includes contact with infected clothing or bed linen. Once it has entered the body it replicates itself in the nose and regional lymph glands, later spreading to other organs of the body where further replication occurs before it spreads to the skin.

Chicken pox is milder and self-limiting in children. Adults tend to suffer more and have a greater risk of complications. Once the infection has subsided the virus sits in the sensory dorsal ganglia of the nervous system for the rest of the persons' life and it can be reactivated as shingles.

Greater risks for patients with RA

Shingles affects 10–30 per cent of people during their lifetime and can cause severe pain and complications. The risk of complications increases with age and illness, and in patients with rheumatoid arthritis and musculoskeletal conditions.

It has been recognised since the early 1990s that severe chickenpox can be associated with steroid therapy. Medications implicated in the development of shingles include methotrexate, azathioprine and cyclophosphamide. It has recently been suggested that methotrexate and biological therapies are unlikely to be a cause, however COX-2 non steroidal anti-inflammatories could be associated.

People who are immuno-compromised are at increased risk of severe and life-threatening illness from the infection. Many patients with active rheumatic diseases are treated with disease modifying anti rheumatic drugs (DMARDs) such as methotrexate that can lower the immune system by suppressing lymphocyte duplication. These patients tend to take DMARDs long term and therefore have an increased risk of developing shingles if exposed to the virus.

If exposed, then what?

A detailed assessment should be carried out in primary care:

- Establish the VZ status of the patient by asking if the patient has had chickenpox or shingles. Ideally, the VZ status of all patients should be checked before commencement of DMARD therapy as some patients may not be immune or have an equivocal result (despite previous contact).
- Advise seropositive individuals to avoid situations where they may come into contact with chicken pox or shingles. Offer vaccination prior to commencing DMARD therapy.

If patients develop chickenpox or shingles, we recommend stopping DMARD therapy until the condition has cleared.

First choice

The initial treatment option for a patient who has come into contact with VZ virus is an antiviral such as aciclovir. Antivirals are mandatory for immunocompromised patients.

If antiviral therapy is started as soon as contact is believed to have occurred, it can reduce the severity of the pain and increase the rate of skin healing. For patients who are not as severely compromised oral acyclovir is considered safe as long as there is careful monitoring.

Intravenous acyclovir is available, but would require a hospital admission and so is likely to be reserved for the more highly compromised or those with no known immunity.

Other treatment options

Second, immunoglobulins can be given. This involves a plasma transfusion containing specialised antibodies. This option is not the first choice because it is difficult to obtain and costly. Ideally immunoglobulin should be given within three days of known contact. Treatment does not give sustained immunity and needs repeating each time the patient is exposed to the virus.

Third, if contact has just occurred, the individual can be vaccinated providing they are not immunosuppressed. Varicella vaccine is 80–85 per cent effective.

There is some concern about vaccinating the immuno-compromised because their immune system may not be able to limit the reproduction of the vaccine virus. This could lead to a potentially fatal vaccine-induced
infection. However, the vaccine may be given in certain circumstances; for instance, patients with a leukaemia in remission.

**EXPOSURE AND RISK**
Appreciable exposure to varicella-zoster virus is regarded as contact with:
- a person with chickenpox or disseminated zoster between 48 hours before the onset of the rash and until cropping has ceased and all lesions are crusted.
- someone with exposed lesions; risk of infection from an immunocompetent person with a non-exposed zoster lesion is remote.
- an immuno-suppressed person with localised zoster (any part of the body) from rash until crusting.

Appreciable contact can be:
- in the same room for 15 minutes or more
- face-to-face contact (for example, during a conversation).

**References**
(All Internet links were accessed 21 May 2008)
7. Heininger U and Seward JF (2006) Varicella, *Lancet*, 368, pp.1365–1376. Editor’s note: This is an excellent piece of work and the full version will be on the Rheumatology Nursing online community when it is launched on the RCN website later this summer.

Continuing our series on the devolved countries of the UK, here’s a state of the nation report from BRIAN RHYS-DILLON, Clinical Nurse Specialist Rheumatology at the Princess of Wales Hospital, Coity R’d, Bridgend, South Wales.

**Wales: Designed for life**

As part of new political philosophy in the UK, the Welsh Assembly Government (WAG) had all power for providing health care devolved in the earlier part of this decade. To help the future for health care in Wales, WAG produced *Designed for life*, which aimed to deliver a world-class health care service by 2015.

As arthritis and musculoskeletal conditions are a major area of disability in Wales, it is imperative that service development and commissioning directives are in place to ensure that our patients receive the highest quality of care.

Like other parts of the UK this has been addressed through our service development and commissioning directives for arthritis and chronic musculoskeletal conditions.

Similarities exist between the Welsh document and the musculoskeletal framework for England, including the early assessment and diagnosis of arthritis and other musculoskeletal conditions as well as prevention/reducing the risks of bone, joint and soft tissue disorders.

**Nurses will have to make it work**

Unfortunately the document did not attract extra funding to ensure its efficacy in maximising optimum levels of health for patients and so we have to be focused and imaginative in how we achieve our goals.

As ever the nursing profession will be central to its ongoing success. This can be illustrated particularly in the area of facilitating and managing independence where patients accept responsibility in their care and can self manage their conditions.

Thankfully groups such as Arthritis Care and the National Rheumatoid Arthritis Society are invaluable in helping patients maximise independence. The NRAS Awareness Week started 14 April in North Wales and finished in South Wales on 17 April. These meetings intended to ensure that patients are aware of what services are available locally and how, when and why to access them in times of need.

We hope this will be the platform for patients to get involved in setting up local support groups and gain a greater understanding and independence in their disease management.

**Main issues for rheumatology nurses in Wales**

Although the rheumatology nurse is the driving force behind a number of patient care initiatives, there is little consideration given to how we engage with organisational panels/ policy makers.

Loss of role identity concerns a number of nurses as nurse managers are unsure of the specifics of the job. As a result a structured career framework is needed, outlining fair and equal pay bands for all, based on generic job descriptions and looking at entry qualifications, experience and so on.

With the merger of a number of NHS trusts across Wales, rheumatology nurses are concerned as to how, when and where nursing care will be provided in the future.

**Editor’s note: Northern Ireland will report in our next edition.**

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**Renal care across communities**

A series of workshops on renal disease and care management

- **Birmingham – RCN West Midlands Region** Tuesday 15 July 2008
  **FULLY BOOKED**
- **Edinburgh – RCN Scotland HQ** Thursday 18 September 2008
- **London – RCN HQ, London** Thursday 30 October 2008
- **Belfast – RCN Northern Ireland** Thursday 4 December 2008

RHEUMATOLOGY COURSES

ARC Graduate Certificate in Rheumatology Practice
This course is for all nurses and allied health professionals wanting to develop their roles in rheumatology, whether in an extended role, specialist or community practice. It consists of six modules at Level 3 ranging from inflammatory disease management to understanding the psychosocial impact of arthritis.

These are distance learning modules with two days teaching content per module, delivered at rheumatology centres around the country.

For details and an application pack contact: arc.course@brighton.ac.uk or Lisa Harford, Course Administrator, on 01273 643772.

MSc in Clinical Rheumatology Nursing
For all nurse innovators seeking to develop their clinical practice, this MSc is accredited through Keele University and hosted at the Haywood Hospital in Stoke on Trent. Modules include:
- clinical effectiveness
- physical assessment
- drug therapy
- psychological issues
- clinical leadership
- research.

Next intake May 2009. For more information and a taster pack, contact the Course Secretary, Kath Jones, at: kathryn.jones@uhs.nhs.uk or the Course Director, Sarah Ryan (Nurse Consultant), at: sarah.ryan@uhs.nhs.uk

The ASPiRE Course
For all allied health professionals seeking to develop their clinical practice. The ASPiRE course is held at Keele University and consists of two degree level modules providing a forum for collaborative learning. The modules are:
- Arthritis and allied conditions
- Management of arthritis

Next intake April 2009. For more information and a taster pack, contact the Course Secretary, Kath Jones, at: kathryn.jones@uhs.nhs.uk or the Course Director, Sarah Ryan (Nurse Consultant), at: sarah.ryan@uhs.nhs.uk

The Arthritis and Musculoskeletal Alliance has announced the publication of the next volume of its Standards of Care documents.

New from ARMA:

Musculoskeletal foot health problems

This document is the result of a project carried out on behalf of the Podiatry Rheumatic Care Association which involved consultation and consensus of the UK musculoskeletal foot health and service user community. It was funded by the Arthritis Research Campaign (arc). The purpose of the standards document is to provide a benchmark by which foot health service standards may be evaluated by all stakeholders. It follows the same format as the other ARMA standards documents in that a series of standard statements are presented that encompass the entirety of foot health service provision, supported by evidence based justification and suggestions for foot health service configuration and implementation.

CONTINUING PROFESSIONAL DEVELOPMENT COURSES

A collaborative approach to management and self-management of arthritis (Level 3 or M)
This successful and exciting module explores how professional and patient resources can be used and co-ordinated by the multidisciplinary team to enable the patient to deal with arthritis. Themes include psychosocial influences, consequences of illness, coping, evidence for patient education, team working and the application of these to the development of professional roles.

Course starts 14 October 2008.
Contact: sarah.hewlett@uwe.ac.uk

Managing individuals with long-term conditions (Level 3 or M)

Supporting individuals with long-term conditions (Level 2)

These modules have been developed in response to Supporting people with long term conditions and Our health, our care, our say (DH, 2005 and 2006). These papers highlighted the need for practitioners to understand and appreciate the core skills and knowledge required to support this diverse client group. The modules explore the impact of social, political, psychological and cultural influences on the care and management of people with a long term condition, including practical issues such as communication and goal setting.

Level 3/M course starts January 2009.
Contact: angela.hudson@uwe.ac.uk

Level 2 course starts April 2009.
Contact: maggie.hehir@uwe.ac.uk

All three modules run over eight days spread across several months. They can be taken as CPD, as part of a degree pathway (20 credits) or un-assessed. All modules are multidisciplinary and have received excellent reports from previous students.

For an application form or if you have a general enquiry, contact:
The Continuing Professional Development and Conference Unit, Health Training and Research Centre, Faculty of Health and Social Care, University of the West of England, Frenchay Campus, Bristol BS16 1QY
Telephone: 0117 32 81158
Email: hsc.cpd@uwe.ac.uk
Website: www.uwe.ac.uk/hsc

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The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies