One of the issues brought to the forefront by the current Pan Thames Haemophilia Consortium Review is the lack of demonstrable evidence for a number of aspects of haemophilia care, particularly the ways in which the service is delivered. Are you surprised? Are you comfortable with it?

One of the regular comments in feedback from our HNA meeting is the wish to hear about haemophilia nursing research. So where is this research and is it something “other people do”? I know I have pieces of work I always intended to publish, but never quite got round to and they’ve been sitting for so long now that surely they’re past their sell-by date. Someone else must have published something similar by now as proper research.

Am I alone in this shameful confession?

Have you ever found yourself talking to other haemophilia nurses at meetings and getting really fired up about an interesting idea you could get together and work on? But it doesn’t quite happen. The reasons why could be about our personal characteristics such as confidence, motivation or creativity. The literature on nurses in general suggests there may also be professional and educational issues, and that barriers may arise from organisational cultures, and concepts and expectations of roles. Of course it might just be that work overload limits the activities of haemophilia nurses.

Most of us are involved in some form of research activity within our haemophilia centres, but it is often related to trials of therapeutic products or it’s within a medical model. This raises the question of what are the legitimate areas for haemophilia nursing research, what could and should our contribution be to the body of haemophilia research and what methodologies should we be using?

You tell us!

Kate Khair, Vicky Vidler, Chris Loran and myself have looked at the whole area of research and publication. As a starting point, while we might speculate about the views and experiences of haemophilia nurses, we don’t really know how much interest and experience is out there or how we might encourage and support each other to be more productive.

By the time you read this newsletter, you should have received a survey by email. We will feed back the results at the HNA meeting in November and facilitate a workshop based on some of the ideas generated.

If you haven’t received a survey yet, contact me so I can send you the link or, if you prefer, a paper copy. I really hope you will be there to participate in the workshop.

Email: christine.harrington@royalfree.nhs.uk
Telephone: 020 7830 2557.

I knew the summer was nearly over when a colleague appeared at my elbow wanting a deposit for the Christmas party! Hope yours has been great and you’re looking forward to this year’s HNA conference which we plan on making as successful as ever.

Apologies if this newsletter is a little slim, but not many of us seem to want to share our experiences – as always, many many thanks to those who have. Don’t wait to be asked. There’s no need to be shy: any contribution – short, long, serious or funny – is valuable and worthwhile so do get in touch (angela.westoby@leedsth.nhs.uk).
SUSAN KAYE, Haemophilia Nurse Specialist from Bradford, suggests a dose of TLC for busy, stressed out nurses.

A prescription for relaxation? Take a spa break!

Recently I had the pleasure of a three-day spa break. I would highly recommend this to anyone feeling a little stressed, tired or in need of some pampering, whether you opt for a single day or short break. I came home relaxed and recovered.

On the first day I indulged in a facial and a back massage. I had never had a facial before and I found it very soothing and it left my skin feeling so good. It was difficult to wake up afterwards, but fortunately there was a lovely relaxation room to laze about in.

On the second day I had a strawberries and champagne body wrap (a bit of a waste, some might say) and a dry flotation, and felt hugely pampered. My friend had her makeup and hair done and she looked great.

Getting hot and steamy

On both days prior to our treatments we spent time in the spa itself. There was also a small outdoor pool, heated to body temperature. It was certainly an unusual experience to swim in a warm, outdoor pool with the smell of the forest and big fat raindrops falling on one’s head. Attached to the main pool was a massaging pool.

Although pampering breaks are a little expensive, they are well worth it when you need some TLC or just some time for yourself. It’s worth searching the Internet and keeping your eyes peeled for any bargains.

Go on, treat yourself!

Of course you could create your own spa break at this year’s HNA meeting.

HNA 2008 is on the way!

This year we’re off to the splendid Hilton Puckrup Hall in Tewkesbury, situated on the edge of the Cotswolds in 140 acres of parkland, just 50 minutes from Bristol, Birmingham and the NEC.

Puckrup Hall is fully equipped with meeting rooms, a business centre and wireless Internet access to ensure our conference is professionally accommodated. It also has its own spa with outdoor terrace, Living Well gym, pool and hot tub – plus an 18-hole championship golf course and fine dining on international fare at Balharries Restaurant. If you can extend your stay and drag yourself away from the hotel itself, Tewkesbury has its own attractions including the Abbey, while a little further afield you can visit sights such as Warwick Castle.

The RCN and You

Come to the RCN Annual General Meeting (AGM) and find out what the RCN is doing for you.

Liverpool Arena and Convention Centre, Monarchs Quay, Liverpool L3 4FP
Wednesday 15 October 2008, 13.30 – 17.30

Register by text
Text AGM2008 along with your MEMBERSHIP NUMBER, SURNAME and POSTCODE to 88020* to book your place.
*Text messages will be charged at your normal network rate.

HNA Annual Conference 2008

7–8 November 2008

Application forms are now available so be sure to return them in good time. Full information from any member of the steering committee or contact Universal Conference and Incentive Travel on 01753 632024 (fax: 01753 655505).
CARYL BERRY in Sheffield reflects on a situation which arose at her work but could happen to any of us.

Experiences with a foreign student: a salutary lesson!

I returned to the Haemophilia Centre from a ward visit the other day to find it unexpectedly occupied by a young Malaysian couple – he was a 22 year-old student with severe haemophilia who had come to complete his degree in Sheffield as part of an exchange arrangement with his home university in Kuala Lumpur.

He had intended simply to introduce himself, but in the process of finding the centre had set off a muscle bleed in his thigh.

I followed our previous practice for overseas visitors in need of treatment, based on the belief that “emergency” treatment can be given free of charge, irrespective of nationality and status.

While mixing up his first-ever dose of recombinant FVIII, we invited a member of our overseas finance department to come and do the necessary paperwork for an overseas visitor. Meanwhile, to go horribly wrong. It transpired that students must be in full-time education for a minimum of six months to qualify for free treatment.

He was told that his visit would cost £122 plus an administration fee of £35, in addition to the cost of any treatment he received. His girlfriend was taken off to withdraw £157 from his account while I continued to worry about the blood test I had already taken and recombinant FVIII already given.

This was not the sort of “welcome to the UK” experience I had envisaged!

I had treated him in the belief that a bleed treated in the haemophilia centre constituted emergency treatment. I had given him 2000iu of recombinant FVIII at 46p per unit – cost £920!

When an emergency is not an ‘emergency’ I was duly informed by finance that only treatment given in an accident and emergency department qualified as “emergency” treatment and this was later confirmed after a phone call to the advice line at the Department of Health.

As a result we hastily cancelled his clinic appointment for the next day and phoned him the following morning to check on the progress of the bleed, instead of seeing him for reassessment and possible further treatment (thereby saving him £122!) Fortunately, the prompt FVIII administration had prevented the bleed from developing.

Meanwhile our visitor had been telling me about his home treatment in Malaysia. He was allowed 6x250iu vials of plasma-derived FVIII at a time, one dose per bleed, two treatments per month. This was free of charge, funded by the Malaysian government. He weighs about 90kg. His main target joints are his elbows, both of which have fixed flexion deformities.

This humbling episode brought several things home to me

Even after recently attending an inspirational and thought-provoking World Federation of Hemophilia Congress in Istanbul, it is sobering to be confronted with the inadequacy of haemophilia management in many parts of the world. We take our gold standard care so much for granted in this country and so do our patients. Many haemophiliacs worldwide have even less access to factor replacement than this young man.

On a personal level, it was deeply frustrating not to feel able to offer the level of care and treatment that I am used to giving, almost without consideration of the cost. Sympathy and kindness are not enough to counteract the pain and potential long term damage of a muscle bleed.

It is best not to make assumptions about someone’s eligibility for treatment based on past experience. Faced with a patient with a bleed, it is easy to shoot first and ask questions afterwards.

In case you’re ever faced with a similar situation ...

The Department of Health has a good website and if I can use it, anyone can! Go to www.dh.gov.uk and, under “Health Care”, find “Entitlements and Charges”

These regulations are legally binding, but ... the responsibility of deciding who is charged for treatment ultimately rests with the hospital providing it.

and then “Overseas Visitors.” There are guidelines for the various categories of visitors based on the NHS (Charges to Overseas Visitors) Regulations of 1989. Here is a very brief summary:

• Students are entitled to free NHS treatment if studying full-time for at least six months or on courses funded by the UK Government. If they are here for less than six months, and from countries...
with bilateral health care agreements, they are eligible for urgent treatment only. A list of these countries is on the website (but does not include Malaysia!).

- Asylum seekers are entitled to free NHS treatment while seeking asylum or appealing against a negative decision. Failed asylum seekers lose their entitlement, although they can have free emergency treatment. People granted refugee status should have the same NHS access as UK citizens.
- People on holiday are chargeable unless from a country with a bilateral health care agreement or needing emergency treatment – they should take out insurance before arriving.
- Emergency treatment should be given to anyone free of charge, but only if carried out in an A&E department or NHS walk-in centre. This does not appear to include haemophilia centres, although many centres provide the primary care for haemophiliacs in need of urgent treatment. Admission to a ward from A&E or attendance at an out-patient clinic is chargeable.

The regulations are legally binding, but all these guidelines end with the disclaimer that the responsibility of deciding who is charged for treatment ultimately rests with the hospital providing it. As in many areas of NHS practice, what you get depends on where you go for it.

Our Malaysian patient has been asked to go to A&E for any additional treatment he needs so he can be given it free of charge. In Sheffield the A&E department is in a separate hospital three-and-a-half miles from the Haemophilia Centre. This is not how we would like our own patients to be managed abroad.

**Postscript**

Since I wrote this article, the Haemophilia Centre has been designated an emergency treatment centre for patients with haemophilia by the Medical Director – at our request. Apparently, this is at the discretion of individual trusts. This means that, although our Malaysian patient would still be charged for anything other than “emergency” treatment, at least he can be seen in a department with experience of assessing and managing haemophilia-related problems. Result!

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### UPDATE

#### The Haemophilia Alliance

Following previous attempts to engage with the new specialised commissioners, Adrian Pollitt, Director of National Specialised Commissioning Group (NSCG), was welcomed to the 18 July meeting of the Haemophilia Alliance by Dr Jonathan Wilde, co-Chair.

His presentation covered these points:

- The NSCG was set up after the Carter Report to co-ordinate commissioning of specialised services, including haemophilia.
- The list of specialised services under the remit of the NSCG is revised every three years and is currently being reviewed.
- The NSCG has expert commissioners and clinicians on its panel.
- The directors of the 10 specialised commissioning groups meet every six months with the NSCG to discuss policy.
- The NSCG produces the national commissioning policies and makes recommendations to health ministers. There are three tiers of policy – mandatory, advisory and good practice.
- The specialised commissioning groups have been tasked with designing specialist services to specific hospitals and this process is ongoing.
- The designation process is overseen by the Specialist Healthcare Alliance.

Discussion took place regarding the possibility of having “protected” centrally-funded services, exempt from the tendering process.

#### Pan Thames Review of Haemophilia Services

It is felt that the current haemophilia service will not be able to continue unchanged because of issues around sustainability of individual provider centres. Following two recent meetings there continues to be discussion about an appropriate model of care in London, but no decision has been made as yet as to the favoured model. It is hoped that consortium leaders will be willing to attend the next Alliance meeting in January and provide some insight into progress so far.

#### Archer Enquiry

There has been a further meeting of the Archer Enquiry and additional documentation has been presented. It is now anticipated that the report will be published this autumn following a review of the documents.

Following the Scottish public enquiry as directed by European Law, it was felt that any ruling would apply to the UK and not just Scotland. This means that it is possible that England will now have to hold a public enquiry also.

#### National contract expenditure

This is on target with prices in the lower price band. The contract is to continue for an extra year, until 2010. Discussion took place relating to the possible arrangements in the new contract to cover any improvement in products and thus a price increase. It was felt that the NHS Purchasing and Supply Agency (PASA) and possibly Deloittes would again be involved in the tendering process, but that owing to a recent European Directive the second tendering process would have to differ from that used previously.

There has been a significant increase in Haemophilia Society membership numbers following the waiving of the annual membership fee. The Alliance is due to meet next in January 2009.
Paul Thurlow is Clinical Nurse Specialist – Haemophilia at the Katharine Dormandy Haemophilia Centre, Royal Free Hospital in London.
A mature lady (which is to say, over 40) gets pulled over for speeding...
Woman: “Is there a problem, officer?”
Officer: “Ma’am, you were speeding.”
Woman: “Oh, I see.”
Officer: “Can I see your licence please?”
Woman: “I’d give it to you, but I don’t have one.”
Officer: “Don’t have one?”
Woman: “Lost it – four years ago for drunk driving.”
Officer: “I see. Can I see your vehicle registration papers please?”
Woman: “I can’t do that.”
Officer: “Why not?”
Woman: “I stole this car.”
Officer: “Stole it?”
Woman: “Yes, and I killed the owner and hacked him up.”
Officer: “You what?”
Woman: “His body parts are in plastic bags in the trunk if you want to see.”
The officer slowly backs away to his car and calls for reinforcements. Within minutes five police cars have circled the car. A senior officer slowly approaches, clasping his half drawn gun.
Officer Two: “Ma’am, could you step out of your vehicle please?”
Woman: “Of course. Is there a problem, sir?”
Officer Two: “One of my officers told me that you have stolen this car and murdered the owner.”
Woman: “Murdered the owner?”
Officer Two: “Yes, could you please open the trunk of your car?”
The woman opens the trunk, revealing nothing but an empty trunk.
Officer Two: “Is this your car, ma’am?”
Woman: “Yes, here are the registration papers.”
He is quite stunned.
Officer Two: “One of my officers claims you do not have a driving licence.”
The woman digs into her handbag and hands the licence to the officer. He examines it and looks puzzled.
Officer Two: “Thank you, ma’am – one of my officers told me you didn’t have a licence, that you stole this car and that you murdered and hacked up the owner.”
Woman: “Bet the liar told you I was speeding too!”

Comings and goings in haemophilia nursing ...
GOODBYE, GOOD LUCK AND HELLO
Congratulations and best wishes to:
• Susan Kaye (Bradford Haemophilia Centre) who is marrying Gary Smith on 4 October.
• Kerry Baker, who has got married, and the birth of her twins was imminent as we went to press.
• Lesley Henderson, who has had a baby girl. Both are at Great Ormond Street Children’s Hospital.
• Dr L A Parapia (Bradford Haemophilia Centre), who is retiring in September.

DATES FOR YOUR DIARY
UK Haemophilia Centre Doctors & British Society of Thrombosis and Haemostasis Annual Meeting
1–3 October 2008
Nottingham
Details from Lynne Dewhurst, UKHCDO Secretariat
HNA Annual Conference
7–8 November 2008
Hilton Puckrup Hotel, Tewkesbury
Details from any steering committee member or contact Universal Conference and Incentive Travel on 01753 632024 (fax: 01753 655505)
RCN IV Therapy Forum
2008 Conference and Exhibition
Tuesday-Wednesday, 18–19 November 2008
City Hall, Cardiff
Download the conference flyer and programme abstracts at: www.rcn.org.uk/events
Contact Pat Anslow on 029 2054 6492
Email: pat.anslow@rcn.org.uk
Booking enquiries: 029 2054 6460

Course postponed!
Unfortunately the Advancing Haemophilia Nursing course planned for September has had to be postponed for logistical reasons. However, it is hoped to go ahead in the spring so if you were thinking of applying you still have time. For more information contact Vicky Vidler on 0114 271 7329.