

April 2014 Issue 2  
Members Newsletter

# southern haemophilia network

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## Welcome to our new Network Nurse Manager!

The Southern Haemophilia Network are pleased to introduce Lara Oyesiku to the team. Lara joined us in December having worked as Advanced Nurse Practitioner at the Oxford Haemophilia Centre since 1996. Lara is a former chair of the World Federation of Haemophilia Nurses Committee, a committee member of the Royal College of Nursing Haemophilia Nurses Association and one of the founding members and previous chair of the Novo Nordisk Global Haemophilia Network Support Committee and current chair of the Bayer European Haemophilia Nurses Advisory Board.



Lara was recently awarded a Roald Dahl Scholarship to further support and educate adolescents with Haemophilia and related bleeding disorders, she used this to produce a film "Bubble Wrap Boy". Please visit our website to view this!

**[haemophilianetwork.org.uk](http://haemophilianetwork.org.uk)**

**Thank you! The Southern Haemophilia Network Team Engagement Day was held on Wednesday 4th March and was a great success! Thank you to all who attended and for the presentations and talks that were given to the team. We received some great feedback from the day and look forward to further successful network events.**

# inspired by excellence

## Announcements!

The Southern Haemophilia Network are pleased to introduce our new receptionist for the Basingstoke Haemophilia Centre, Nicola Aldridge joined us on the 3rd of February.

The location for the next Southern Haemophilia Network Board meeting will be at Queen Alexandra hospital, Portsmouth on Tuesday the 2nd of June.

## Meet the Team—Melanie Wilkinson, Clinical Nurse Specialist



Melanie was awarded an HNA research bursary last year. Her study was aimed at gauging parental confidence when dosing their children prior to sporting activity. It involved children with severe Haemophilia using long acting factor products. Mel is still recruiting for this study and would be happy to discuss with any colleagues who would be interested. Further information on the study is attached with the newsletter.

**Hire** out our meeting room at Vickers House, charges for non-SHN members are £50 for a half day or £90 for a full day. Costs include hire of room, tables & chairs, wi-fi, projector and flip charts. For SHN members complimentary tea and coffee is provided.

Got an announcement to make? Email us at [email@haemophilianetwork.org.uk](mailto:email@haemophilianetwork.org.uk)

To explore parental confidence when dosing children with severe Haemophilia A and B with long acting factor products, before they participate in sporting activity.

The goal of haemophilia in childhood is to prevent or minimise spontaneous bleeds in a cost-effective manner which is practically acceptable to the child and his parents. Understanding of factor pharmacokinetics with both short and long-acting products has advanced and the principles of scientific factor dosing in relation to exercise are understood.

Use of short acting factor products may have fixed certain dosing strategies in relation to exercise in the child and parent's mind. These beliefs and practices are poorly understood and this issue becomes particularly relevant as we move into the era of long-acting products where an instant 'fix' of treatment immediately prior to exercise may not be necessary.

Aims are to help Haemophilia Nurse Specialists learn from children with haemophilia and their parents how we should advise and support on future factor care in relation to sporting activity. This pilot study offers an opportunity for in depth focussed interviews. It is hoped that this study will generate insight into targeted interventional strategies which could be tested on a larger patient group.

Eligible parents of boys with severe Haemophilia A or B under the age of 16, participating in or previously participated in clinical trials for long acting factor product for at least six months will be identified in two participating centres using purposive sampling which involves the selection of participants who have knowledge or experience of the area being investigated.

A qualitative research method will be proposed for this study using a naturalistic inquiry of semi-structured interviews to allow an in-depth investigation. It is estimated that the study will take approximately 12 months to complete.

Funding is by the Haemophilia Nurses Association.