Welcome to Blood Matters Autumn 2017!

Welcome to the first edition of our bi-annual newsletter from the Oxford Adult and Children’s Haemophilia Centre. We are dedicated to providing information to all patients who have a bleeding disorder and for their families and carers.

We are working hard at the Haemophilia Centre to provide a high quality clinical service. In parallel we also run many clinical trials which has meant that many patients have had early access to cutting edge medications that have since become treatments of choice for patients.

We are proud of the services we offer, but there is always room for improvement and we value your input. This will help shape our future services and guide research.

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We recently held a patient and public involvement meeting, and would like to say an enormous thank you to all those who attended and for their superb contributions towards making it a successful evening.

Discussions and ideas generated during the meeting are being considered further to improve and develop our services. We share the feedback and minutes on the following pages. We look forward to hearing any further comments or suggestions from you.

Finally, for all those who are affected by the parliamentary inquiry into contaminated blood products, we are here to help and support you. If you would like to request your own or an affected family member’s medical notes please contact the Haemophilia Centre and we can guide and direct you through the process.

Patient and Public Involvement Meeting May 2017

The meeting started with three short presentations

Consultant haematologist, Dr Nicola Curry, set the stage by discussing patient involvement and its importance in research and patient care. New haemophilia treatments, novel and gene therapy was explained. Ideas were presented on how to improve services and communication between the Haemophilia Centre and patients.

Children’s haemophilia specialist nurse, Alice Wilkinson, discussed some initial ideas in developing or improving patient information leaflets in areas such as transitioning from paediatric to adult care, pregnancy, travel, head injury, physiotherapy and exercise, guidance on medication such as tranexamic acid, and port-a-caths.

Other areas of service provision included shared pregnancy care and shared adult/paediatric transition clinics – what is helpful when transferring care from child to adult services.

Senior physiotherapist, Stephanie Taylor, presented ideas on musculoskeletal health, how to increase physical activity and joint health, best type of exercises and intensity and what would motivate physical activity or sport for patients with bleeding disorders. Ideas about setting up exercise classes or guidance on use of equipment at local gyms were discussed.

Main outcomes

Consensus was that all those who attended enjoyed the meeting and found it useful. It captured a snapshot of differing views and thoughts on current services and how they can be further developed.

It was noted that a chance for patients to meet and converse with other patients, parents or carers of people with bleeding disorders informally was helpful. A desire for further such meetings was expressed – future patient and public involvement meetings or patient gatherings are to be organised.
Creating small focus groups or working parties to encourage patient input was considered, for example a research group, patient information leaflet group, a social media group etc. Patient volunteers are needed, please contact the haemophilia nurses if you are interested.

An interest in focusing on primary research and generating research from the Oxford Haemophilia Centre – finding answers to questions about improving care was raised by staff members and patients.

Stephanie Taylor (physio) expressed an interest in setting up an exercise focus group which would help with advice on exercise support for patients. Maybe setting up hydrotherapy or gym classes at the Nuffield Orthopaedic Centre – please contact Steph if you are interested.

A desire for increased communication between the Haemophilia Centre and patients was conveyed. Ways to increase communication, including issuing a newsletter, updating the trust website and the safe use of social media, such as Facebook / YouTube / Twitter and apps is currently being explored. Patient volunteers to help guide and review content would be useful.

Generic emails for patients to contact the respective haemophilia teams for feedback and non urgent matters are available for use.

Children’s centre: paediatric.haemophiliaclinic@ouh.nhs.uk
Adult centre: haemophilia.reception@ouh.nhs.uk
             oxford.haemophiliaclinic@ouh.nhs.uk
Most people were keen to have improved patient information leaflets in various areas and for them to be easily accessible such as the internet – these leaflets will be developed by the adult and children’s haemophilia nurses / physiotherapist with patient volunteers to help review the content before circulation to the wider patient and public audiences.

Some patients expressed that they were happy to share their own experiences of haemophilia with other or younger patients – the creation of an ‘expert patient’ database was considered to put patients who would like support or advice from other patients in touch with them.

A lack of knowledge of exercise and types of exercises haemophilia patients can do was voiced. An information board in the patient waiting area is to be created by Steph, physiotherapist, featuring patients and what they manage to do — see poster on page 5. Additionally exercise advice information sheets will be created.

Some patients and parents or carers asked for closer links with the Haemophilia Society and Oxford Haemophilia Centre, in regards to information disseminated about research and issues with duplication – a link nurse has been nominated to address this.

Patients also raised the point that the local ‘Oxford Haemophilia Society’ branch was not functional and unsure of the members, lack of interest and finding convenient places to meet. Interest in resurrection of the group was aired.

If you would like to participate or would like to create or join a focus group or like to be a patient volunteer to review and contribute to our patient information leaflets or content of our websites or social media, please do get in touch on the contact numbers and email addresses provided.
We want your photos!

To display on our patient information board at the Haemophilia Centre. Do you have a bleeding disorder and enjoy exercising or sports?

Email: stephanie.taylor@ouh.nhs.uk
We will let you know and ask your permission before we use your photos for a display on the patient information board at the Haemophilia Centre.
Clinical research is about looking for new ways to treat or prevent diseases. These treatments might include new drugs, new procedures or devices, or even new ways of using existing treatments. The goal of a clinical trial is to determine if the new test or treatment works and is safe.

I spoke to one of our patients who is currently involved in a clinical trial about how he found the experience. **So, why did you want to be in a clinical trial?**

I took part in the trial with the hope of reducing the amount of FEIBA and NovoSeven I was taking. The doctors and nurses at the Haemophilia Centre were genuinely excited about the clinical trial and this gave me hope that taking part in the study could be a breakthrough in the way my condition was treated.

**Did you find that there were any difficulties taking part in the trial?**

The main difficulty I found was finding the time to attend hospital for the study appointments. At first these appointments are frequent, so I had to make sure that I could schedule well in advance. As the study progressed these appointments have become less and less frequent and are now entirely manageable. With the help of a supportive employer I now don’t see the appointments as a difficulty whatsoever.

**What do you feel you have got out of being in this trial?**

I can’t stress enough how much I have got out of the trial. I only have had one (activity related) bleed compared to my treatment before the trial and I am now ten months in. The study drug gives me much more confidence that the pain, swelling or soreness in my joints isn’t a bleed and it can be remedied with some relaxation and ice. I’m now leading an almost entirely normal life. I’ve been able to exercise more in the past ten months than at any other time in my life and I’ve been able to build up strength with far less fear that I was overdoing it.

Before the study there was no doubt that I was over-treating myself, but I just didn’t feel like I could take the risk of dismissing niggles or swelling. It always felt better to minimise the risk and treat myself, rather than to be off my feet for weeks at a time. I’ve been so grateful with the time saved by taking part in the study – I don’t think I fully appreciated how much time preparing and administering medicine truly takes. I no longer have to set an alarm an hour earlier than necessary to do prophylactic treatment!

**Do you have any last things to say about trials?**

Yes, though it can be a challenge, in terms of the time commitments involved, it can and has made a real difference in my life. I now live an active life, and my bleeding disorder plays a much smaller part.

This is only one person’s experience. Everyone’s experience will be differ slightly. If having read this you would like to talk to anyone about taking part in a study then please don’t hesitate to call the centre and ask to speak to one of the research team or bring it up at your clinic next appointment.
Prickles club update

The aim of Prickles club is to provide an opportunity for families caring for pre-school children with haemophilia and Von Willebrand disease to socialise with each other and to share their personal experiences in an informal environment over a coffee.

We currently meet three times a year; we last met in June. We have since emailed and posted out a survey to Prickles club patients for their feedback on the club. These results will help us to improve the club to better meet their family’s needs.

Learning to self-infuse

We held a fantastic bowling day out in July with children aged 6-14 years old, who are interested in learning to self-infuse their own factor treatment. The children had fun bowling and socialising over lunch and then listened to a brief talk on self-infusion.

Children were also able to practice intravenous access on a dummy arm, Bay-Cuff kits, on willing volunteers or themselves!

The event was successful with positive feedback from all those who attended. We are planning follow-up and new sessions for children who wish to practise or learn.

Let us know in clinic if you would like to attend the next self-infusion day!

Look out for our new ‘giving yourself factor’ photo guide and video - coming soon!
Other useful information:

To reschedule or cancel clinic appointments please give us one week’s notice via our email address or telephone below.

This enables us to offer the appointment to someone else.

Safety hats for young severe haemophilia children are completely optional. They can be useful as they learn to walk.

Other parents have recommend the Thudguard protective safety hat. More information can be found online.

Moving to adult services?
Are you READY…..STEADY……GO?

Transition is the process of preparing, planning and moving from children’s to adult services. We use this programme in the Haemophilia Centre, it is designed to help you gain knowledge and skills to manage your condition independently, as you become an adult. You will be supported by the doctors and nurses throughout the process.

Visit: http://haemophilia.org.uk

Paediatric.HaemophiliaClinic@ouh.nhs.uk
Telephone: 01865 226562 / 234212

If you are changing schools please let us know in clinic or via email and we can arrange a school visit by one of our children’s haemophilia specialist nurses or contact them and send information as required.
Haemtrack can help ensure you’re receiving the best treatment

and can benefit your clinical care

Haemtrack is a useful online tool or mobile app for people with bleeding disorders who use factor concentrates at home, to record when and how they use their factor, for example prophylaxis or for a bleed. **Important information**

Your doctor or nurse will review your Haemtrack records with you during your clinic appointment. This will help you easily remember the timing, reasons and how many bleeds you have had in the last six months or when you were last seen in the clinic. It will also help decide if there are any gaps in protection or missed doses, which might have led to breakthrough bleeding, or to have better factor cover on days where you might be more active, for example going to the gym. It is important to enter your prophylaxis or bleed treatments in real time or as close to the infusion time as possible. The specialist nurses and physiotherapist at the Haemophilia Centre proactively review Haemtrack on a daily basis and may contact you to give you further advice or support. The additional questions asked when recording a bleed, such as the pain score or filling in the comments box with the reason for treating, the amount of swelling or pain, the range of movement are all helpful to ensure you are taking the right dose.

For advice or support using Haemtrack, speak to your haemophilia nurses. For contact details see pg 11
Meet the Haemophilia Team & Contact details

Adult Haematology Consultants

Dr Nicola Curry
Dr Susie Shapiro
Dr David Keeling

Children’s Haematology Consultants

Dr Georgina Hall
Dr Neha Bhatnagar

Adult Nurses

Joanne Burke
Sayma Raza-Burton
Karena Carter

Children’s Nurses

Marie Eales
Sarah Pool
Alice Wilkinson

Nursing Research Team

Simon Fletcher
Chris Springett-Deane
Agnes Eordogh

Physiotherapists

Stephanie Taylor
Lisa Gueran

Staff Updates

Goodbye Kayleen!

Many of you will have heard that our colleague Kayleen has left the Haemophilia Centre to take up a new post in rheumatology. We would like to say a big thank you for all the excellent work she carried out for our patients and the centre. Finally, we congratulate her and wish her all the best in her future role.

Claire Rogers, our adult physiotherapist has also left to start her masters degree, we wish her best of luck. She will be replaced by Jenny Harper, who is coming with a wealth of experience from the Nuffield Orthopaedic Hospital.

Sayma Raza-Burton has been appointed as the new haemophilia senior specialist nurse. On a final note, Joanne Burke will be retiring in October. We are sad to see her go, but wish her a very happy retirement!
Contact details: Monday to Friday, 9.00am - 5.00pm

**Adult Haemophilia Centre:**
*Reception:* 01865 225316 (for appointments and enquiries)

Nurses: 01865 225309 *(for advice or treatment)*

Mobile: 07776135752 *(office hours only)*

Email: Haemophilia.Reception@ouh.nhs.uk
Oxford.HaemophiliaClinic@ouh.nhs.uk

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**Children’s Haemophilia Centre:**
*Secretary:* 01865 234212 (for appointments and enquiries)

Nurses: 01865 226562 *(for advice or treatment)*

Email: Paediatric.HaemophiliaClinic@ouh.nhs.uk
*(emails for non-urgent use only)*

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**Out of Hours: Emergency advice or treatment**
*(outside office hours, after 5.00pm, weekends or public holidays)*

0300 304 7777

OUH switchboard, ask to speak to ‘specialist haematology registrar on-call’

www.ouh.nhs.uk/haematology/services/haemophilia