



FACTORS

THE NORTH WEST GROUP OF
THE HAEMOPHILIA SOCIETY NEWSLETTER
WINTER 2011 EDITION

Chairman's Chat

Hello all, thank you for another busy year for the North West Group with fundraising events, donations, and a thoroughly enjoyed family weekend; but 2011 hasn't stopped yet. The Prestwich Conservative will be hosting the Las Vegas Evening on the 25th November as well as the Christmas Party and AGM on the 18th December 1-5pm. If you would like to get involved and put yourself forward as a committee member the North West Group would love to have you, contact info@haemophilianw.co.uk for more information. If you come to the AGM you can find out what the North West Group has been up to and also discuss plans for next year and have your say on how funds are spent in your area; if you bring children we will keep them occupied before the party starts. This year we had the NW Group Family Weekend in September where it was great to see 22 families meeting up, taking part in workshops and having a day out at Camelot Theme Park, you can read more about this on the next page. David Fielding has kept the committee up to date on all campaign issues and this year attended some key meetings with the Department of Health and MPs. In June I went down to London with Graeme Kerby and David Fielding to attend the launch of Fit for the Future: Bleeding Disorder Services in the New NHS which was very informative about the planned changes for commissioning services for bleeding disorders and purchasing of treatment. Here's to another fantastic and proactive year for the North West Group, bye for now. There are a selection of photographs from the Family Weekend on the next page.

**Michelle Semmens
Chairman**

North West Group Weekend 2nd to 4th September

The North West Group hosted a family weekend in September and welcomed members from the North West and other areas in the UK. 20 families attended the event along with committee members and volunteers. The Weekend would have not been possible without kind donations, fundraising events and part funding from a legacy left to us by Mrs Hall. There was a mix of leisure time and interactive workshops and the food and accommodation provided was great. I would like to say thank you to the workshop leaders on the Saturday; Dr Bolton-Maggs (Manchester Royal Infirmary), David Henderson (Haemophilia Society), Christine Cammiss (Royal Manchester Children's Hospital) and Nigel Pegram (Haemophilia Society) who shared their knowledge and expertise in different aspects of living with a bleeding disorder. Three volunteers, Sue Kerby, Caroline Meachin and Peter Semmens looked after the age 7 to 13 age group with indoor and outdoor activities including games, crafts, films and a games console throughout the day. The Mobile Creche Company provided a crèche for 21 children aged from 3 months to 6 years and were flexible in meeting our requirements. The weekend was topped off by a sunny visit to Camelot Theme Park.

**Michelle Semmens
Chairman**

Comments

We all had a fantastic time on the camelot weekend! Thank you to Michelle, Pete (aka Dave) and Sue and everyone else involved for your hard work and input into delivering the weekend and thank to all the families for making it a success. My son really loved making new friends and he said he liked 'not being the only kid with haemophilia' or 'feeling like the odd one out'. I am really looking forward to our Northwest group Las Vegas evening now. Going to get a babysitter n enjoy myself!! Xx

Really enjoyed the weekend

Lovely people and great time had by us all

Thanks to everyone who was involves in organising it all and took time to speak to us all on Saturday at the workshops



Above and Left:
Photographs from Workshops

Top Left:
Photograph from Camelot

Keeping Fit

I have been to a number of conferences and events on treatment of bleeding disorders where physiotherapists all advocate regular exercise and maintenance of an active lifestyle, so I thought it would be fitting to do a Factors feature on this. We all know it's important to regularly exercise and the Government is now telling people that they need at least 30 minutes of exercise a day. However I am acutely aware that many members are struggling to cope with fused joints, arthritis, chronic pain, sporadic bleeding episodes, inhibitors and the effects of contracted viruses. All of these circumstances as well as others have an effect on motivation, physical ability and stamina.

Some Haemophilia centres have excellent links with physiotherapy departments, with some running microclinics and this is great as individual patients get tailored plans to suit their ability level and capability.

This way exercise can be used alongside factor treatment to speed up mobility and relieve pain following bleeding episodes. While this is fine in the clinic what happens between clinics or after you have overcome that problem? Many people find that they do not even get to see a specialist physio at all. There is no way round it going to the gym and having a fitness instructor to create a programme and motivate you is going to cost time and money.

Many Haemophiia patients rarely see their GPs and in most cases it is not about Haemophiia and it concerns me that there is a great service available which is ideal but people just aren't accessing it. I have raised this point at events and the majority of people have not heard of the scheme or have been dissuaded by their GPs as patients are told they will not receive specialist care. There are schemes around the country where local authorities work with health services to run a fitness programme at local leisure centres. Referrals to the scheme can be made by GPs and in some cases by physiotherapists. I am asking members to let me know whether they have used such a programme, would like to use it in the future or even already knew that this service existed. The North West Group can feed this information back to commissioners and Primary Care Trusts so that there is a greater understanding of what's out there. I know that specialist medical areas such as diabetes, cardiology, rehabilitation following injury are already using it so why aren't we? I look forward to hearing from you on this matter.

Michelle Semmens
Chairman

Money Matters

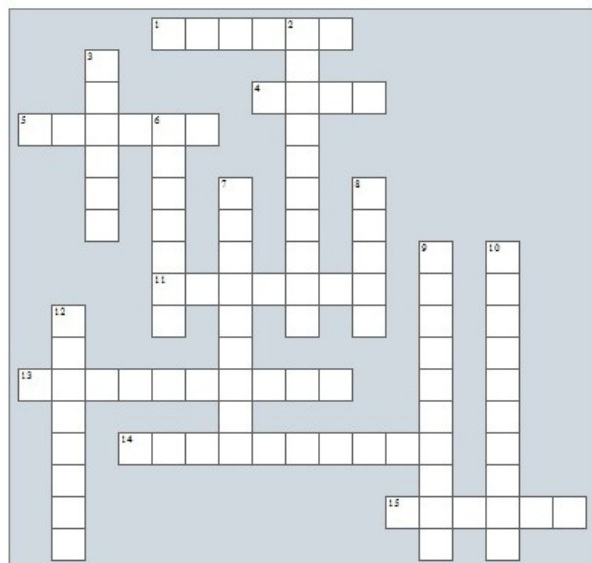
The North West Group has had another great year in terms of fundraising and donations bringing in over £4800 including a donation of £1000 from the Westwell School of Dance, £1900 from the South Caernarfon Soroptomist Group and £800 from the Big Lottery Fund. The Family Weekend at Camelot +cost a total of £10,000, everyone enjoyed themselves and found the workshops available useful. We hope that our family weekends/days out will become regular annual events.

There will be more chances to fundraise, with the Las Vegas Evening, which will be held on the 25th November. All details on where to buy a ticket and the location of the event are online. You can pick up a copy of our annual accounts at the AGM on the 18th December for a full breakdown of income and expenditure.

We have been an active group for many years and it is thanks to volunteers that we have been able to continue to support our members through days out, family weekends, respite breaks and purchases of medical equipment. We also support our members who continue to lobby and campaign on behalf of all members in the North West.

**Peter Semmens
Treasurer**

Factors Crossword No. 1



Across

- 1. Brazilian River (6)
- 4. Eboracum is the Roman name for this city (4)
- 5. Alexander _____ Bell, telephone inventor (6)
- 11. Himalayan Peak (7)
- 13. King's Speech Actor (10)
- 14. Tourist Attraction in Venezuela (10)
- 15. Delete, oust (6)

Down

- 2. Part of the Earth's atmosphere (10)
- 3. Speak highly of; laud (6)
- 6. Anagram of Married (7)
- 7. Costly (9)
- 8. Data, truth (5)
- 9. Cinderella Character (10)
- 10. Mirror image (10)
- 12. Curb (8)

This crossword puzzle was created by Haemophilia Society NW Group with EclipseCrossword. Try it today—it's free!

Winter colouring in page





THE
HAEMOPHILIA
SOCIETY
NORTH WEST GROUP



Come and Join Us at our Annual Christmas Party and AGM

1-5pm Sunday 18th December
Prestwich Conservative Club
Church Lane, Prestwich,
Greater Manchester, M25 1AN



Each child will receive a present
from Father Christmas

Pick up a form to register your place

www.haemophilianw.co.uk

Our Committee

Michelle Semmens - Chairman
David Fielding - Vice Chairman
Glenda Greenhalgh - Secretary
Peter Semmens - Treasurer
Graeme Kerby - Editor
Chloe Drury - Co-Editor
Sue Kerby - Fundraising Officer
Dr Bolton-Maggs
Paul Clare
Simon Cox
Julie Kirkham

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Las Vegas Evening Friday 25th November, 8pm

Prestwich Conservative Club
Church Lane, Prestwich,
Greater Manchester, M25 1AN



Tickets cost £4 including supper

Roulette, Black Jack,
Greyhound Racing,
Texas Hold Em,
Raffle, crazy auction



www.haemophilianw.co.uk

THE HAEMOPHILIA SOCIETY
NORTH WEST GROUP WEBSITE

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www.haemophilianw.co.uk

- Meet the committee
- Fundraising events
- Factors newsletter
- Haemophilia Centres
- Travel information

