



FACTORS

The Newsletter of the North West Group

ISSUE 13

The North West Group magazine devoted to male and female bleeding disorders.

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Chairman's Chat

by Norma Guy (Vice Chairman)

It does not seem like 6 months since Alex wrote the last chairman's chat but believe me it is, as vice chairman I have stepped into her shoes for a short while.

Fund raising has been kept to a minimum as there have been some ill health amongst the committee, Michelle (Treasurer) has been in and out of hospital, she is now mobile, at least on an elbow crutch, David Fielding has been in hospital having his ankle fused so all in all it has seemed like the 'Battle of the Somme' But we are slowly getting back on the track.

The respite weekend went extremely well as Paul will explain later in this newsletter. Our website is

nicely up and running so check it out. The newsletter will be on site and you can order it on-line or continue to have it posted.

Towards the end of this newsletter you will see the AGM date and Christmas party and it would be lovely to see more of you at the AGM - which is held in the bar area. There will be someone in the big room who will keep watch over the children while the AGM is in progress.

We would be grateful for help with fundraising and we also need some helpful new members on the committee. If any of you would like to think about it we really would appreciate the help. *Norma Guy*

Stairway To Heaven by Paul Bullen

I have never been scared of heights so last year when my ankle was giving me so much pain, to the point I could hardly walk, I rang Social Services to enquire about having a stairlift fitted.

I did not really think that they would agree to fit one without delay, if you have ever tried claiming DLA you will have some idea of what I was expecting. When the Occupational Therapist visited me at home I thought I will need to put forward very good reasons for needing one because I don't really look disabled; I just walk with varying degrees of a limp. However I explained that when my ankle is really bad - or I have a bleed somewhere else - I have genuine problems getting up and down stairs. How many haemophiliacs have come down the stairs on their bottom? O.K. so you all know what I mean. I added that sometimes I had trouble balancing and there is a real possibility that, one day, I would fall.

I also explained that there were times when these problems are magnified because I suffer from muscle fatigue as a result of my 'liver problems'. Maybe I have an honest face, or maybe it was because I was able to show the Occupational Therapist the Factor VIII in my fridge, that, much to my surprise, she gave her approval straight away. Ten weeks later it was fitted.

It has made such a difference. Using it all the time has taken so much stress off my ankle, and saved

some of the little energy I have, that I feel so much better; less pain and a bit more energy may not seem very significant, but as an aging haemophiliac I am happy to settle for that.

The stairlift has been a real benefit to me. If you decide to follow my example and feel things are not going too well inform (politely) the Occupational Therapist of the cost of factor replacement therapy. If you did fall on the stairs the cost of your treatment will be far more than the cost of a stairlift. I didn't need to say that but it is worth knowing.

If you do apply just beware that you may be 'means tested' before you are offered a grant.

Paul Bullen



TEN YEARS ON *(AND STILL GOING STRONG)*

By David Fielding

I can't believe that I am here writing this article. Why because I have reached a milestone in my life and I am celebrating the 10th anniversary of my liver transplant.

On the 10th of October 1998 I got on to an operating theatre trolley at 8.00am Saturday morning. I had what was to be my last shot of factor 8 at six in morning. Boy has time flown by. What has having a liver transplant done for me? It has enabled me to see my children grow into young adults. Both my wife Maria and I have been able to foster 2 children for 4 years and that has given us the opportunity to do something in our lives that has given us so much pleasure to help others when they needed it. To me I feel that it's given me a sense of purpose, something I can look back on and feel proud.

I have tried throughout my life to help others as much as I am able. I do get a lot of pleasure in putting something back. They were at the time of my illness, 9, 6, and 5. You imagine what I went through mentally. I had to face up to the fact that my young ones were maybe, going to lose their dad, they were too young for that to happen. I think that's partly what got me through in the end, stay strong for them and make it, because they will need you. I always had this belief that I would get through and my life would be saved. I will be forever grateful to my donor and the donor family. What they did for me was such an act of great compassion and thoughtfulness. They really must have had this desire, and love for life. I

have tried my best to keep myself as well as I can and watch what I eat and drink. Talking of drink, I would love to get drunk one night and have a fat head the day after, but I wont, because I feel I owe it to my donor to seize and not abuse "the gift of life". I did an interview with my local newspaper the other day and I found it so emotional and distressing talking about those dark days when I was so ill with liver disease. I had to stop a few times as I was in a bit of what we all call "lump in the throat state". Revisiting the bad times in your lifetime, but I did it to really highlight that so much good can done if there was more people on the organ donor register.

The public need to be more informed and educated in how organs are retrieved. How the body is treated with such dignity and care. Transplant coordinators from different centres go and retrieve the organ they need. This involves more than just going in there, taking everything out and sending it to the hospital by carrier pigeon. I will always be ever grateful to St. James hospital in Leeds for all the care I have received both pre and post transplant. I have always been treated with dignity and the utmost respect.

When you sit in the clinics and look at all the patients who have had transplants you see what life is all about and how they are living. We would not be here but for the skills of the surgeons, the after care we receive. Thank you The Liver Unit, God bless you all. *David Fielding*

The Archer Inquiry

By David Fielding

I would now like to talk about the Archer inquiry, which is still ongoing. I have attended every session, including the opening announcement except for the short afternoon session when I was on holiday.

I gave evidence on the first day of the inquiry. Because I had a lot of photographic evidence when I was ill with liver disease due to being infected with both hepatitis "B" and "C". I wanted the inquiry team to see for themselves what it was like dying from one of the infections that have hit the haemophilia community so hard. I told them that I also lost a dear brother with HIV and because hepatitis

nearly killed me, I thought and believed that our family had suffered enough and it was about time we had either had our day in court or a full and open public inquiry into why over 1, 757 had died from contaminated blood products. There is no doubt in our campaigners minds mistakes were made and blood product safety was violated. I have actively been involved in campaigning for around 14 years now and still we wait for an end to this awful chapter in our lives. Any government has never dealt this with and it's about time it was addressed. Too many have gone to their graves with no sense of justice. That's an-

cont...

The Archer Inquiry (cont)

other one of the reasons that I have been to most of the inquiry days, as it's also helping me to come to terms and learning about what went wrong and how so many others got caught up in this tragedy.

Sitting and listening to others who have suffered just as much as myself and how the public treated innocent Haemophiliacs who had been contaminated with a virus in the course of their treatment was born out of sheer ignorance and I feel sick that the public treated those in such appalling way.

Shame on those who did it. I could write in this article some of the instances that they went through, but it would make for poor and upsetting reading. To this day people are still suffering from the effects of yesteryear and I feel that there should be some form of "after the event" counselling. Even though I am a strong person myself I feel at times events have got to me and that's when I have felt

low, and needed to talk to someone. I have to thank our former North-West group chairman Norma Guy for being such a great listener and an ear to pour out your feelings.

We want to do some regular features in the newsletter on HCV and it would be appreciated if some of you would send in an article, idea or topic to discuss. I know I haven't got haemophilia anymore, but what I have is this desire to be as active in the haemophilia community as much as I can. My phone number is at the back of the newsletter.

I also would like to sign off by saying that I hope some of you who are worried, even scared about your future regarding living and suffering from Hepatitis and having a transplant, take heart from my situation, I have reached 10 years and aim to go on for many more. I am at the end of the telephone if you need to speak to me.

David Fielding

CHILL OUT WEEKEND

Over the second weekend of September the Group held a 'Chill Out Weekend' at the excellent Upper House Hotel, Barlaston, Stoke-on Trent.

You may be thinking 'I never heard anything about this'. This is because we did not ask for applications from our membership, instead we asked for nominations – in the strictest confidence – from the Haemophilia Centres in our area.

Why did we organise it this way? Well, your Committee felt that your treatment centre nurses were the best people to help us to achieve our objective, which was to make places available for the families who would benefit the most from a completely chilled out, relaxed weekend. The main criteria we used were to ask the treatment centres to nominate families who had recently been through a particularly difficult time as a result of haemophilia, for example, a prolonged illness.

If we said it was a 'great success' you may think 'well they would wouldn't they'. However there were

By Paul Bullen

no lectures, no workshops, no medical professionals; everyone was free to do exactly what they wanted. This created a very relaxed atmosphere and the 12 families appeared to really 'jell'. We hope they all benefited from the experience.

We would like to take all the credit for the idea however we must thank the late Hollywood actor Paul Newman for the inspiration. He founded the Association of Hole in the Wall Camps for families who have to deal with a long term medical condition. Generous fundraising and sponsorship allows families to have a complete 'get away from it all holiday' without having to worry about their medical condition or the cost. In our own way the North West Group tried to create our own little Hole in the Wall Camp.

We would especially like to thank one very supportive nurse (you know who you are) and Ann, the extremely supportive lady who owns the Upper House Hotel, for making the weekend possible.

Paul Bullen

Moving up to Adult Care *Graeme Kerby*

I moved over to the Manchester Royal Infirmary Haemophilia Centre in May this year at aged 17, after feeling very conscious that I was outgrowing the Haemophilia Centre at RMCH.

I used to sit in the tiny waiting room there looking round at the other patients and feeling that I had nothing in common with them, especially with the train set and children's books taking pride of place in the corner. At 6 feet 4 inches tall, I was too tall for the height chart and my legs too long for the examination bed. I had enjoyed my time at Pendlebury and made some friends

along the way but it was time to move on.

My first time at MRI, I decided to attend the appointment alone as I didn't want my mum or sister fussing over me, however I found things work a little differently there and went straight to the Haemophilia Centre only to find my appointment was at the outpatients, I was completely lost in that huge building.

I have been to the centre a couple of times since and have just started to get my bearings. I would be happy to talk to anyone who is worried about the move over to adult care. *Graeme Kerby*

Haemophilia Society North West Group Questionnaire

The Haemophilia Society North West Group distributed 400 surveys earlier in the year to our membership to identify patients' experiences of Out of Hours Accident and Emergency care.

The aim was to determine awareness of Haemophilia and related disorders in general and specialist hospitals within A&E departments across the region. We received 39 responses and some patients attended more than one hospital in the region. The majority of responses came from adult attendees (72%), however the 28% of paediatric patients represented 6 out of the 9 hospitals covered in the survey. Responses were mainly concentrated in the Greater Manchester and Liverpool area with some from North Staffordshire, there was no response from North Wales or Cumbria.

The majority of responses were from patients who attended Manchester Royal Infirmary and Royal Manchester Children's Hospital. Local A&E hospitals included Royal Oldham Hospital, University Hospital North Staffordshire, Blackpool Victoria and Leighton hospital.

Those surveyed were asked questions on their experiences during their last three visits and responses were grouped into years to 2003 and then grouped before 2003. 52% of patients said they had to wait less than 1 hour to see a doctor, and just fewer than

20% had to wait less than 2 hours. However there were some cases where patients had to wait more than 4 hours without receiving any treatment.

67% of patients had to explain about their condition to the doctor at A&E and 19% said they did not have to explain, 14% did not provide an answer. 44% were satisfied with the treatment they received at the time and 33% were not satisfied with their experience. General comments were fairly positive on the whole with patients who attended A&E departments where there was a Haemophilia Centre present in the hospital, feeling they had been listened to seen promptly. However the majority of those who attended local hospitals had to define Haemophilia and how they treat themselves/ their child.

There were often delays whilst doctors tried to contact specialist hospitals or waited for Haematologists to attend. Some people were unhappy about the level of communication between the A&E doctor and themselves and felt they had to wait for too long to receive treatment. Other issues which arose from the survey were that some patients did not realise that they could speak to the Haemophilia doctor on call at their Haemophilia Centre. Others also felt that their Green Cards were not recognised by paramedic and A&E staff. A copy of the full report can be obtained from info@haemophilianw.co.uk *Michelle Semmens*

The Inhibitor Support Group Weekend

The inhibitor support group weekend was this year held on the 4th and 5th October at the Royal Court Hotel in Coventry. This was our family's second ISG support weekend away and we as a family have gained so much out of them.

The ISG was developed by the Haemophilia society and Novo Nordisk who have worked in partnership for the last 3 years. The project was relaunched this year in Solihull Birmingham. People with inhibitors are the most isolated within the Haemophilia community. The group has 160 members on its database. The aim is to provide information, support, financial help, advocacy and raising awareness.

The knowledge and support we gained from hearing other people and families experiences living with an inhibitor has been invaluable. The support and just talking with fellow sufferers who are not only living with burden of having Haemophilia but the added impact of an inhibitor on top.

The weekend provided us with information and support and also the added bonus of listening to the experts who gave talks on their own specialised fields. One of the talks was about Nova 7. Lara Oyesiku, who is an advanced specialist nurse at the Oxford centre, gave a demonstration on the new Novo Seven product. The treatment does not need to be stored in the fridge and it can be stored at room temperature for 2 years, without affecting the stability. I can see the treatment in a

first aid kit in the boot of a car. Lets hope that in the future factor 8 can be made and stored in the same way. The advances in our Haemophilia treatment has come on so much in the recent years and what it has done is let the haemophilia community lead almost a normal life.

The rest of the programme for the weekend included a DVD and discussion on removal of a ureter stone by ISG member David Henderson that was really interesting. Ian D'Young Specialist Physiotherapist and Alex Whittle from Baxter healthcare gave a presentation on fitness and physiotherapy.

What I liked about the programme was the presentations by ISG members on their experiences of orthopaedic surgery and we all gained from learning from others. A final presentation was from Gareth and Georgina, Empowerment patient/doctor control, which was lively and fun and we all participated in. The hotel was really nice and we all had quite a relaxing time. We all take away from the weekend, knowledge that we didn't have before and also the support we gave one another.

On a sad note we had to say good-bye to the Haemophilia Society worker Jane Matheson who has put a lot of work not only the ISG but also many other tasks at the office. She has been a great listening ear for many others and me. The good advice and information will be remembered forever. Good luck in the future Jane. *David Fielding and Family.*

ANNUAL GENERAL MEETING

The Annual General Meeting of the North West Group of the Haemophilia Society will be held on Sunday 14th of December at 1.00 pm and will immediately precede the Christmas Party.

Members who wish to be nominated for the group committee should contact:

Michelle Semmens (sec), 47, Huntley Mount Road, Bury BL9 6HY Tel. 0161 768 4434

The Christmas Party



The Group's Annual Christmas Party will again be held at Swinton Masonic Hall, Hospital Road, Pendlebury on the 14th of December 2008, at 2.00pm. There will be party games and refreshments. There is a comfortable bar for the adults and music and games for the kids. The afternoon will be rounded off by a visit from Father Christmas.



Remember, the party is for everyone - not just for children.

If you wish to come, please fill in the enclosed slip and post it back to; Norma Guy, 43 Hereford Road, Heaton, Bolton BL1 4NJ

YOUR COMMITTEE

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Come and Visit the North West Group's New Website

A colour version of the Newsletter is now available to download from this website

This Newsletter costs the group over £100 in postage, which we believe is money well spent. If you would like to receive a pdf. colour version of FACTORS by email, in place of the black and white version you receive by post, please send an email to:

nwgroup@tiscali.co.uk - giving your name, postcode and email address.

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