

Who too!

for young people affected by bleeding disorders

Global Feast



Thursday 17th April was World Haemophilia Day. World Haemophilia Day is celebrated on this day as it is the birthday of Frank Schanbel who started the World Federation of Hemophilia. It is a chance to teach people about haemophilia and other bleeding disorders as well as to raise money for bleeding disorders. This year the day was celebrated across the world with a global feast.

In Ireland, New Zealand, Canada, Australia and the UK people held pizza parties, picnics and barbecues to raise money to help people in their own countries and across the world with their bleeding disorder. Here in the UK we had a big party in London and more than 100 people came for dinner to find out more about bleeding disorders.



One of our fundraisers Beth with BJ, the nurse at Kent and Canterbury Hospital.



What other bleeding disorders are there?

Most of you will have heard of haemophilia or von Willebrand's but there are lots of other rarer bleeding disorders that people have.

Here Paige tells us what its like to have Glanzmann's Thrombasthenia

My name is Paige and I am eight years old. I have Glanzmann's, it is very hard having Glanzmann's because I can't eat hard things and I have lots of nosebleeds.

When I wake up in the morning I have blood on my pillow and clots on my teeth and I have to have tranexamic acid and lots of other medicines. When I clean my teeth in the morning my toothbrush makes my teeth bleed. All this blood in my mouth makes my breath smell funny, so I have to use a minty mouthwash to make my mouth smell nice.

If my brothers Aaron and Kian hit me I get lots of bruises and bleeds and I have to put ice packs on them. At school I can't sit on a hard floor so I have to sit on a cushion, also I have people to look after me at playtime 'cos it's crowded in the playground and I might get pushed over and could get hurt.

I have two dogs called Milly and Daisy and a cat called Morris. I have to be very careful that they don't scratch me. My nose is a pain - if I sneeze it can make my nose bleed. I can't press on the bleed 'cos I don't know where it is coming from so I have to go to hospital to stop it.

Sometimes I am there all day and night having platelets to try to stop the bleed. My nurse is called Kate, she is at Great Ormond Street, this is my hospital.

Paige, 8, Glanzmann's

*FAST FACTS*FAST FACTS*FAST FACTS*

- What is Glanzmann's?** It is when the platelets in the blood don't work properly
- What are platelets?** Platelets are like glue that clots the blood
- What are the symptoms?** People who have Glanzmann's can bleed for longer from even small injuries
- How is it treated?** Glanzmann's can be treated with DDAVP when bleeding is mild but if the bleeding is serious the person will be given platelet infusions.

Hello from the Society....

This year has been a busy year so far at the Haemophilia Society as we've moved to brand new offices in a new part of London. Look out for the photo of our new office on page 3. This means we've got a new address and new phone numbers so if you want to get in touch with us then make sure you use the numbers on the back page but the freephone helpline number has stayed the same.

Moving offices was a very big job and took a long time but it was worth it as our new office is bigger and a lot nicer than the old one.

So far this year we've had the first of our activity weekends at Mill on the Brue in Somerset and everybody had a really good time. I've heard you were all very good at grass tobogganing and that you also had a go at canoeing, archery and much more, I bet you were all tired out when you got home. You can read all about it in Bertie and his brothers article on this page. If you fancy trying new activities and going on an adventure weekend then we still have 2 more weekends over the summer so why not show the advert on page 3 to your parents and see what they say.

In this edition of HQtoo! Paige tells us all about having Glanzmann's, there are lots more bleeding disorders than haemophilia and von Willebrand's and it is interesting to hear Paige's story. If you've got something to tell us about your bleeding disorder I'd love to hear from you.

I hope you enjoy this edition and if you've got any idea of what you'd like to see in the next edition let me know.

*See you next time,
Anna*

Contact me on:

anna@haemophilia.org.uk

or call 0800 018 6068 or write to me at:
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ZGTG-ZHJS, First Floor, Petersham House,
57a Hatton Garden, London, EC1N 8JG

Our exciting weekend in Somerset

On the 1st-3rd April the Haemophilia Society organised for us to go down to Somerset on an activity weekend. There were 20 people affected by bleeding disorders from ages 8-13. We arrived at 4pm and were shown our bedrooms, where we unpacked our luggage. There were 12 of us in our dorm and we all had bunk beds.

We had 2 instructors called Tracy and Dave (Big Dave). They gave us a tour around Mill on the Brue and that was when we started introducing ourselves to one another. That night food was on the table at 6pm, we had soup and homemade bread for starters and chips, broccoli and sausages for the main course- yum yum! Afterwards we went for a walk around Mill on the Brue before coming back and having hot chocolate at 9pm and going to bed at 9.30pm.

The next day we were woken at 7.45am and had breakfast at 8am. Our first activity was human table football. It was fantastic - we were strapped onto some poles on a wire which could move from side to side. Next we went grass tobogganing on a really steep slope. We lay on a board with wheels underneath and went whizzing down the slope. Break was next and then we went straight on to low ropes. Low ropes are close to the ground and you had to complete a course but you had stoppers to stop you from falling onto the ground. Then we went on to the archery range. The arrows were light so it was difficult for them to go through the air. Then we went canoeing in the river Brue. We got into pairs, grabbed a canoe and played games on the river.

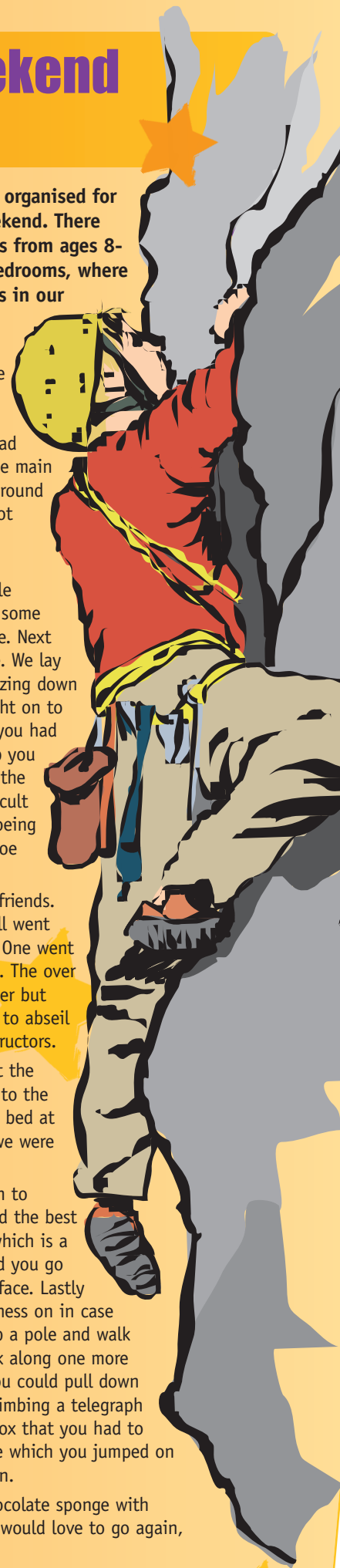
Lunch was next and by this time we had all made friends. Climbing was the last activity of the day and we all went over to the climbing wall. There were 2 routes up. One went simply straight up, the other had a huge overhang. The overhang was difficult to get over, some people got over but most of us didn't. When we got to the top we had to abseil down which was fine but you had to trust the instructors.

Supper was delicious and we were all talking about the fantastic day we had just had. Then we walked up to the day visit barn where we played games. We went to bed at 9.30pm and went to sleep straight away because we were shattered after a wonderful day.

On the last day we woke at 7.45am and went down to breakfast. This was the last day and they had saved the best activities until last. Firstly we went on Zuper Zip which is a 600 metre long wire in the air. It is superb fun and you go so very fast that you can feel the G-force on your face. Lastly we all went on the high ropes where we put a harness on in case we fell. The first thing you had to do was climb up a pole and walk along a beam then climb up another pole and walk along one more beam. It was great fun and it was fairly easy as you could pull down on the rope to balance. The second activity was climbing a telegraph pole which had foot holes. At the top you had a box that you had to climb on to then a metre away there was a trapeze which you jumped on to, not many people made it. Then we got let down.

Our last meal was soup, bangers and mash and chocolate sponge with chocolate sauce. It was a fantastic weekend and I would love to go again, thank you Haemophilia Society.

Bertie (13), Tom (11) and Fergus (10), Severe haemophilia A



Getting on with home treatment

Home treatment is one of the best things that can happen to someone with haemophilia, as it gives you more freedom and the chance to be independent. I have had home treatment since I was the age of 4, but as soon as I was five I could do it all myself. Home treatment has certainly changed my life because soon I am going to Australia with my friends for a whole month!! As you can see being able to do your own treatment has its advantages!!

So if you're not doing your own treatment, get started soon and you might have great opportunities like me.

Adam, 14, Severe haemophilia A

Top tips on home treatment

Have you got any stories about learning to treat yourself or any top tips for anybody who's learning now? Send us in your stories and if it appears in the next edition of HQtoo! you will get a Fred beanie toy.

Activity Weekends

There are still places on our 2 summer activity weekends for 8-13 year olds. The weekends are for people with a bleeding disorder, carriers, their brothers and sisters or anybody whose parent has a bleeding disorder. About 20 people go on each activity weekend along with a group leader and 2 haemophilia nurses. You'll get a chance to try lots of different activities like abseiling, canoeing, archery, raft building and loads more.

This year we've also got a special activity weekend in a TV studio, where you can learn to present and make your own TV programme.

There is a small charge for the weekends but for anybody who can't afford to go the Society can help out with the cost. If you would like to come along ask your parents to ring the Society for a booking form or download it from our website.

8th - 10th July, Aberfoyle, Scotland

12th - 14th August, Burwell House, Cambridgeshire - TV PRODUCTION

And if your brothers and sisters are moaning that they're too old for these weekends then tell them about our new weekend for 14-17 year olds, where they'll get to go caving and climbing in Yorkshire:

29th-31st July, Cowling, North Yorkshire

The Society's new office

Straight after the Christmas holidays the Society moved to new offices. We'd been at our old offices for 8 years and thought that it was time for a change. We moved only a few miles away to Hatton Garden in London, this part of London's famous for selling expensive jewellery and some of the shops even have bodyguards on the door to make sure there are no robberies. It took nearly a whole week to move all of our stuff and we used nearly 230 boxes to carry everything. Now we're all settled and here's what the new office looks like. We're on the first floor.



COMPETITION TIME

The winner of the last competition was Aaron from Shropshire who won a Roald Dahl Treasury. Congratulations Aaron. In this edition the boy in the picture is setting off on an activity weekend but can you spot the 12 differences between the pictures? Send in your entry to the address at the bottom of the page, not forgetting your name and address by Friday 3rd June and you could win some great games.



DRAWING COMPETITION

Thank you to everyone who entered the Fred drawing competition. The winners will be announced very soon.

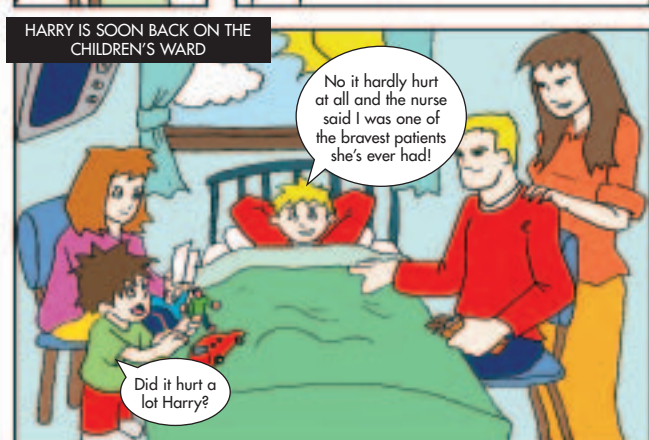
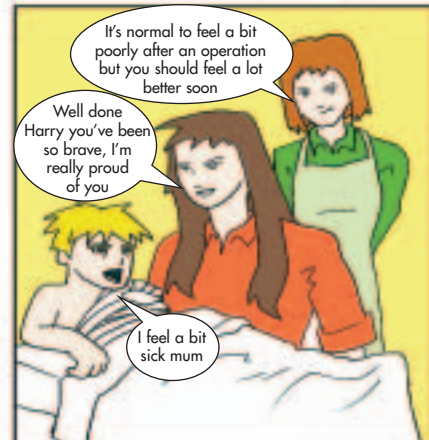
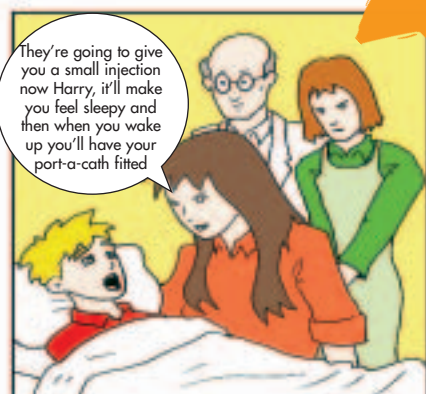
Can you spot 12 differences between these pictures?



Meet Harry... Harry is having his port-a-cath fitted at the hospital.



HARRY'S MUM WAITS FOR HIM IN THE WAITING ROOM



Next time: Harry's mum learns to give him prophylaxis at home.



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