

How too!

for young people affected by bleeding disorders

You probably see a lot of your haemophilia centre and the nurses and doctors there and know them pretty well. As you get older you might have to move to a different hospital or be seen by different doctors and nurses, who are used to seeing adults instead of children. Some times this change can be a bit scary. In Bristol the adult and children's haemophilia centres have tried to make the change less worrying.

Mary, Emma and Anna the nurses in Bristol tell us all about this...

We are Mary, Anna and Emma, the nurses from the Bristol Haemophilia Team. Anna is the Children's Nurse and Mary and Emma are the Nurses from the Adult Centre. At Bristol, the Haemophilia Centres are separate buildings linked by a long corridor. In Bristol we feel it is very important that all adolescents are well supported up to and during the time when they move from the Children's Hospital to the Adult Centre. This time is known as the transition phase. It can be a scary time as you leave a safe, well-known place to go to one that is unknown to you, and it is a time when there are so many different feelings and emotions going on.

The teenage years are a great time to gradually become more independent and responsible for things you do in life. Looking after your health is just one of these things. To do this really well, you will need lots of information about haemophilia or other inherited bleeding disorders and the chance to take over some of your care, ready for transfer to the adult services. Together, as nurses, we have set up a programme to help support adolescents registered at the Bristol Centre. We call this programme 'Getting Independent.'



Emma and 2 fellow Explorers'

At the Children's Haemophilia Centre, between the ages of 11 -18, we aim to give teenagers the opportunity to talk and learn about all different aspects of haemophilia and other related conditions, how it affects them and how to manage their care. We have developed a booklet that aims to put all these things together so we can be sure nothing is missed out. We aim to work through the booklet with each teenager over the years, starting at 11, through to the time when they are ready to transfer to the Adult Centre.

Our other main aim of the 'Getting Independent' programme is to get teenagers to know and meet the adult team before transferring to the Adult Centre. We do this by the adult and children's teams working closely together with the teenager and their family during hospital visits and by arranging social events for you.

Luckily, we have recently won the David Stern Award for our work with teenagers and the transition phase. This was a £1000 award and has helped us to plan exciting days for teenagers with haemophilia and other inherited bleeding disorders (without parents!!!). We spend a day at a great venue where the teenagers can meet new friends and also get to know all the Haemophilia Nurses. We are very excited and hope it will be a huge success.

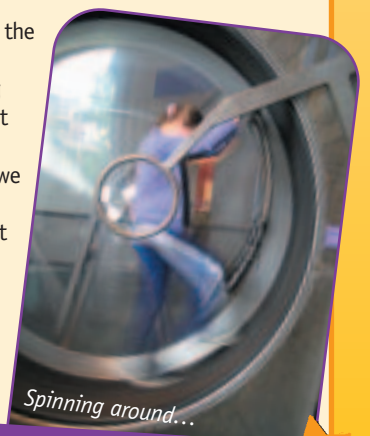


The whole group together

Tom recently went on one of the trips they organised to the Explore Centre in Bristol...

My day at Bristol began when I set off on the bus to get there. On the invitation it said meet by the stag beetle sculpture at 10.15, I checked my watch and the time was 10.00 so I waited by the stag beetle sculpture. Ten minutes past ten lots of people came. So we waited a bit longer for the rest to come but there wasn't any sign of anybody so we got a drink in the café and eventually the last few people came. We bought the tickets and went into the Explore part of Bristol. I had a great time. The water part was my favourite bit especially the hamster wheel that took water from the bottom pool to the top one. At 1.00 we went to the Firehouse and got something to eat. I had a barbecue chicken pizza it was delicious. I also had lemon sorbet. When we had all finished we went outside and played on the robots, I won!! We then went in the shop and were picked up at 3.15. It was a fantastic day out.

Tom, 12, Moderate haemophilia A



Spinning around...

Hello from the Society....

It's been a busy summer here at the Society and we've been lucky to meet lots of you at our activity weekends and the national conference. It's been really good fun and hopefully we'll get to meet even more of you next year. At this time of year I start to plan where all the activity weekends should be next year and when they should be. It's a big job and takes a long time, I look at all the evaluation forms that parents and everyone who went on the weekends filled in to see what you liked and didn't like. If you would like to see an activity weekend in your area or at a certain time of year then let me know and I'll see what I can do.

Very soon I'll be sending out applications for the Sports Awards and Philip Morris Award for arts. You don't have to be Wayne Rooney or Kelly Holmes to win one of the awards but just show that you try hard at a sport or art. When the form comes through your letterbox in the next few months ask your mum, dad, grandparents or even a family friend to nominate you and you could be a winner!

In the rest of this edition there's more news from some budding reporters at our activity weekends. This time Alex tells us about one of our new weekends where everybody got the chance to work in a real TV studio and make their own programme. Harry tells us about his summer playing cricket – is this better than football? As usual there are lots of jokes and your chance to win with our competition on page 4.

We're always looking for people to write and tell us their news and stories in *HQtoo!* so if you've got something to say send me an email or a letter at the address below.

See you next time,
Anna

Contact me on:

anna@haemophilia.org.uk

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

Does your brother or sister have a bleeding disorder?

Sometimes it is not easy being the one without the bleeding disorder but Sibs is a charity for brothers and sisters of people with any medical conditions or disabilities. They understand that you might feel left out sometimes, or jealous of the amount of attention your brother or sister gets from your parents.

This is normal and lots of brothers and sisters in your position feel this way. Here are some top tips adapted from Sibs for dealing with this:

Do you find it hard to understand your brother's or sister's special needs?

- Ask your parent for information about your brother's or sister's bleeding disorder. A parent may have already told you things but as you get older you may need to know more details.
- Does a nurse or health worker come to see your brother or sister at home? Tell that person you want to know more about your brother's or sister's condition and treatments.
- If your brother or sister is ill a lot you may be worried that he or she will get worse. Tell your parent that you are worried and that you need to talk about it.

Do you get angry or upset about your brother or sister sometimes?

- It is normal to feel angry or upset at times. Other siblings feel this way too.
- Even though you love your brother or sister, sometimes it's difficult living with him or her.
- You will feel better if you talk to a parent or another caring adult about these feelings.

Do you want more time with a parent?

- Ask your parent if he or she can spend a little bit of time with you each day. This may be when your brother or sister has gone to bed.
- If your brother or sister goes away or is out ask your parent if you can do something special together at this time – like going shopping, or going to a café or going swimming.
- Tell your parent that you would like him or her to watch you in the school concert or at sports day or some other special event.

Do you feel guilty about enjoying your own life?

- It is very healthy to do things that you enjoy.
- It is good to have friends and interests outside of your family. If you have fun and enjoy your life, you will be happier when you are with your brother or sister.
- Make sure to tell your parent about the things you do well in at school, and at any clubs you go to. You deserve to be praised for your achievements.

There can be good things about having a brother or sister with a bleeding disorder too; you might learn skills in first aid or you might get a chance to meet other brothers and sisters and make friends. Let us know the good or bad things about having a brother or sister with a bleeding disorder at anna@haemophilia.org.uk.

You can find further information on Sibs at www.sibs.org.uk



Getting kitted up for caving



Testing your balance



Shooting some pool

Too old for our activity weekends? If you'll be 13 or over by next summer don't worry we now have an activity weekend for our older members (13-17). Here's a few photos from this summer's mountain activity weekend.



Mastering abseiling

Broadcasting at Burwell...

My weekend away at Burwell House was brilliant! I have done three other weekends and this tops them all!

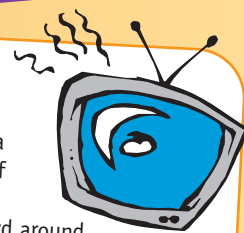
We did everything there from mental challenges to building a craft to launching an egg from the top of the fire escape stairs! But the best bit was when we did a mock-up TV program!

We were given the brief of creating a news broadcast but were allowed to make-up news, and some of the stuff that came out at the end! [The best was probably the mad axe man in one of the rooms there!] We took it in turns between the two groups, filming and acting. The poor director and camera operators! My group made them do about 30 camera changes, whereas they only made us do 4!

There was still the safe knowledge that if I did have a bleed there were people there that knew what to do if such a thing happened, and it was good to know that other people around you knew and they wouldn't crowd around, asking why you had to be whisked away for what appears to be a tiny cut. If you have never been on an activity weekend before, or just fancy a change from the other ones, try this one next year (but leave space for me!)

Alex, 11, Severe haemophilia A

If you were at Burwell House and haven't received a DVD of the news broadcasts get in touch and I'll send one out – Anna.





The big get together...

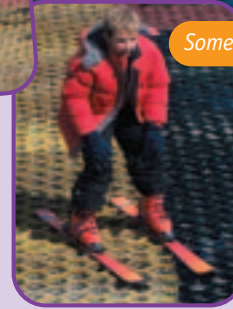
60 of you aged between 2 – 17 came along to our national conference in September. Everyone under 8 stayed at the hotel both days and did fun activities like face-painting, arts and crafts and dressing up, while all those over 8 went out for the day on Saturday. We had an amazing time first having a go at skiing on a dry-ski slope. The big slope we saw as we pulled into the car park put a few people off but once people were shown the smaller teaching slope and the instructors had explained everything nobody could wait to get going. After just 2 hours of lessons we could see that there were some natural skiers, as some of the group managed jumps on the way down. It was hard work though and it was nice to sit down and rest at lunchtime. After lunch it was off to the bowling alley where a balloon artist kept everyone entertained between their goes and then back to the hotel to be met by parents.

By Sunday everybody had made friends and spent the morning swimming, doing arts and crafts or relaxing in the chill-out room.

We had a really good time and hope we'll see lots of new people next year!



Some people had a natural talent!



I love cricket

Over the Summer England went cricket mad but some of our members have always loved cricket. Harry Stephens was runner up of the Society's Sports Award in 2003 for all his effort in cricket and since then Harry has just got better and better, here he is to update us:

Hello I am Harry, 11, I have got severe Haemophilia A. I've played cricket since I was 2 years old, but I've played for a team since I was 5 1/2. I have played for Surrey youths since 2003.

I used to play for Valley End Cricket Club, but then I moved to Camberley Cricket Club. I've played for Camberley for 4 years. I now play for Camberley Under 11's, U12's, U16's, U17's, Saturday 3's and Sunday 2's(both adults). I scored 358 runs and 24 wickets for Camberley kids (colts) this season. I played 9 games for the seniors and scored 31 runs.

I've also played 31 games in 3 seasons for Surrey. This year I only scored 33 runs, that's because I only got to bat 4 times and I gained 5 wickets. Altogether I've got 613 runs and 25 wickets. I've scored 3 fifties for Surrey. My most successful season was in 2003. I scored my first ever fifty against Middlesex. I also won player's player award for the Under 9's, which was very good. 2004 was also a very good year for me, I've got 8 man of the match awards.

I have also played with my dad for The Mayor of Spelthorne. That day I also got to bat with him. I got my highest ever total in a senior game, 14 runs, my dad got 77 runs. We put on a partnership of 64. When I was fielding an U13 Surrey player hit a ball just a bit to the side of me, then my hand started stinging. I realised I'd stopped the ball, only because I was stupid enough to stick my hand out to stop it.

I was very excited when England won the Ashes because they hadn't won it for 16 years.

Haemophilia doesn't need to effect you when you play cricket if you wear the right equipment when your playing with a hard ball, also if you have your injection before you play you shouldn't be any different from anyone else.

I have been selected for a South of England spin bowling seminar, I have also been invited to an assessment course for Surrey under 12's.

Harry, 11, Severe haemophilia A

If you want to try cricket remember to wear a helmet and be safe.



What do you think – is skiing too dangerous?

So some of you might be thinking that skiing when you've got a bleeding disorder is pretty dangerous and that your doctor or parents wouldn't allow you to go skiing. At the conference there was a debate on whether people with bleeding disorders should

be able to do sports like skiing if they really wanted to. It was a tricky debate; some people thought that people with bleeding disorders should never do sports like skiing because they were too dangerous and might cause bleeds. Having more bleeds means using more treatment and this is very expensive. Other people thought that it was better that people had the chance to try these sports and see if they liked them. They said that sports like skiing could be safe if you learn properly and wear proper clothes and equipment and it's good exercise to. In the end 69 people said skiing should be allowed and 55 people said it shouldn't be.

Obviously there are some sports like boxing and rugby, which are dangerous even if you don't have a bleeding disorder but can be even worse if you do. If you've ever watched a rugby or boxing match on the telly you'll know what I mean! And you shouldn't really do these sports but what do you think ... should you be able to try sports like skiing or do you think this is just too dangerous? Cut out the box below and send it in to us to let us know what you think.



- I think people with bleeding disorders should be able to try sports like skiing.
- I don't think people with bleeding disorders should do sports like skiing.

Because:

Cut this out and send it in to the following address (you don't need a stamp as we've already paid for the post) and if your answer is drawn at random you'll receive a great prize.

Send to:

Anna, Freepost RLTI-ZGTG-ZHJS, The Haemophilia Society, Petersham House, 57a Hatton Garden, London, EC1N 8JG

COMPETITION TIME

BEND YOUR BRAIN WITH SUDOKU

This is a new craze with adults but why not show them how much cleverer you are and have a go at the puzzles below. Don't worry you don't need to be a maths whiz; it's just logic.

Send your answers in to Anna at the address at the bottom of the page by Monday 21st November for a chance to win another great voucher. If you can't finish them all don't worry just send in what you've done and the person who's got the furthest will win. Good luck!

Well done to Lewis from Aberdeen who won a £20 Virgin voucher by finding all the words in our summer holiday word search.

How to play

Every column, row and mini grid (that's the squares between the thick orange lines) must have the number 1, 2, 3 and 4 in them only once. Can you complete the grid.

3			
4			1
1			4
			3

Q. What runs but never walks?
A. Water!

This one needs even more brainpower. Same rules as before but this time use the numbers 1, 2, 3, 4, 5 and 6.

	1	3			2
5	3		6		
4	2				
				1	5
		5		2	4
2				3	

Meet Harry...

Harry's mum takes him to the hospital to learn how to use his port-a-cath.



Next time: Harry meets Wendy again at his clinic appointment.

Q. What do you give an injured lemon?
A. Lemon-aid!



HQtoo! is produced by the Haemophilia Society, First Floor, Petersham House, 57a Hatton Garden, London, EC1N 8JG
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