COMMUNITY MATTERS

A parent's journey:

Glanzmann's Thrombasthenia

Plus a focus on wellbeing with Dr Sarah Whitaker

Inhibitors, local groups, inquiry news and more...

The Haemophilia Society

At a glance

Brand new

At our November AGM we unveiled a new look for the Haemophilia Society (THS), after more than 50 years. You'll see from this magazine that our design and logo are a bit different and we've brought in some fresh colours to create a contemporary and welcoming feel.

Research had told us that we needed to make some changes to the way THS was presented, to better reflect our goals.

We therefore spent 6 months asking the opinions and testing ideas with our members, partner organisations and wider audiences, to create the look that you see here.

Redeveloping our brand gives us an exciting opportunity to build the profile of our charity and bring more supporters onside, including reaching more members, sponsors and donors, ultimately enabling THS to survive and thrive. Let us know what you think.

Gene Therapies

Data from the phase 3 gene therapy trials in haemophilia A and B have continued to show some promising results but have also raised questions on how long the increased factor levels will last.

Some trials have shown wider than expected variability in the results people were getting, while all trials have been unable to fully answer questions on the long-term effect and safety of gene therapies.

One trial (Pfizer/ Sangamo) has been paused and others are looking to gather longer-term data before publishing results. In general, these unknowns mean that it is likely that gene therapies, particularly for haemophilia A, will take longer to be licensed and made available to patients.

In the longer-term, gene therapies may also be available for von Willebrand disorder (VWD, also known as von Willebrand disease) and early work is underway on a number of technologies that may make this possible.

Treatment for von Willebrand

We expect more people with VWD to be offered recombinant von Willebrand factor (VWF), slowly reducing reliance on plasma-derived blood products. It is currently being used for on-demand treatment and for surgery, but we hope

it will be available for prophylaxis in the near future.

However, we have seen a continuation of the global shortage in Desmopressin (DDAVP) nasal sprays, leaving many people without access to this treatment option.

The main alternatives are subcutaneous or intra-venous DDAVP, which are available in haemophilia centres, and the hope is that more people will also be able to use subcutaneous DDAVP at home.

We are also seeing new products in development which will give options to treat different types of VWD with targeted treatments. There is preclinical work ongoing on extending the half-life of VWF in people with type 1 by bridging VWF to Albumin. In type 2B there are new strategies to improve platelets counts which will soon go into Phase 3 trials. Early limited trials are also underway in treating Type 3 VWD with Emicizumab.

AGM & forum

Given the backdrop of the pandemic, our November 2021 AGM was held as a hybrid event, with members able to attend in person or join live online.

Although many people were understandably still not keen to travel or attend events, it was very enjoyable for the members, trustees, ambassadors and THS staff who did attend in London to meet in person again.

It was also gratifying that despite 'zoom fatigue', many members also joined the AGM and workshops online.

THS Chair of Trustees Clive Smith gave an overview of the 2019-2020 period, recognising what a difficult year it had been operationally for THS, not least holding events and fundraising during a pandemic.

THS Treasurer Gordon Dixon then outlined the organisation's finances, which he reported were in a reasonable position: a small surplus was achieved despite the very restrictive climate.

Next, Chief Executive Kate Burt looked to the future; including launching THS's new identity, plans to diversify sources of income, and ongoing work to revitalise the local group network. Finally, Kate took questions from the floor and participants online.

The afternoon's session allowed participants to choose from a variety of discussions, from the latest guidelines around VWD to physiotherapy best practice.

All sessions can be viewed at **haemophilia.org.uk/events/annual-member-conference/**

Local Heroes

We know that the ups and downs of living with a bleeding disorder are easier together, which is why our national network of local groups can be an invaluable support network, helping to lessen the isolation that you can sometimes feel if you are affected by a rare condition.

Run by people with real life experience of living with a bleeding disorder, our local groups are designed as a fun, safe space for people to get together, share their struggles, swap tips and even raise money for the cause together.

Unfortunately, over many years, our local groups network has waned, but we are committed to reversing this trend and we are pleased to be supporting several areas to get a local group up and running.

If you're interested in meeting up with a local group, please email Julia at **info@haemophilia.org.uk** for information.

If there isn't yet a group in your area, then why not start one? Two (or more) heads are better than one so whether you're teaming up with another family, friends or clinicians at your treatment centre, it all starts with reaching out to people you know want to make a difference.

Then, just let us know. We'll send you a handy new start-up pack which tells you everything you need to know, and an allocated member of the team will support you every step of the way.

There's a step-by-step guide to getting a social media account started for your group, and simple info on what you need to set-up the group's basic structure, from finance to a yearly event and AGM.

Finally, choose an activity and make it happen. This could be anything from a fundraising event to a meet and greet coffee morning, or simply a picnic in a park.

Whatever you decide, we can work together

to make it fun, and get people supporting each other in your local area.

Any questions or suggestions? Please email Debra or Julia at **info@haemophilia.org.uk**

Meanwhile, you might take some inspiration from two of our local heroes, the Yorkshire Local Group and the Lincolnshire & East Midlands Local Group.

Spolight on Yorkshire

At the start of 2021, a core group of dedicated members got together to reinvigorate the Yorkshire Local Group.

Today it is very active across the region, with hundreds of families and individuals getting involved in regular activities and networking.

The team began with a fantastic idea to raise money for the group's activities, as well as funds towards a local portable ultra-sound scanner. Called 'Race Around the World', the challenge generated £5,000 and lots of awareness about bleeding disorders.

Opposite you can see local heamophilia centre physios Anne and Thuvia performing planks in return for sponsorship!

Events organised by the group are welcoming and inclusive, from Escape Room games for older members, to celebrating Yorkshire Day with a big get-together. Email **BleedingYorkshire@gmail.com** to find out what's coming-up next.

Spotlight on Lincolnshire & East Midlands

With lots of new families coming on board, the Lincolnshire Local Group has voted to become the Lincolnshire & East Midlands Local Group, welcoming individuals and families from right across the region to come together.

The group is also forging strong ties with its nearby haemophilia centres, so that it becomes a powerful support network and source of friendship locally.

Val, pictured here, is the main contact for the group and would be very happy to hear from you if you'd like to find out more. Val was diagnosed with von Willebrand disorder at the age of 57, and has been a stalwart fundraiser for many years! Contact Val and the group at **Lincsandeastmids@Haemophilia.org.uk**

Compensation will be key issue for 2022

Compensation is likely to be an ongoing theme both inside and outside the Infected Blood Inquiry this year.

Many of you have already contributed to the independent study of options for a compensation framework which will be handed to the government in March.

The study, carried out by Sir Robert Francis QC, is the first step towards the adoption of a compensation scheme by the government.

It wants a system in place by the end of the inquiry, which is now expected to be mid-2023. Sir Robert will give evidence to the inquiry about his study later this year.

Discussing compensation has been emotional and difficult for many of you, who have waited a long time for this complex issue to be acknowledged by government.

To make sure we understood and represented your views, we produced a survey which was completed by more than 400 people.

The opinions voiced in the survey were used in the submission we made to Sir Robert about compensation in December 2021. Thank you to everyone who took part.

Our compensation survey highlighted some key areas of agreement:

- 81% wanted existing support schemes to be kept in place
- 95% wanted a "significant lump sum" paid upfront as soon as possible
- 93% agreed anyone infected or significantly affected can claim compensation
- 84% wanted psychological support included in compensation package

Other issues were less clear cut. Opinion was split on how compensation should be awarded.

About 30% of respondents thought it should be based on a

"Whichever method is used, it needs to be prompt and efficient and not force people to dig over old ground."

Anonymous comment from our compensation survey

series of set tariffs, 10% favoured an individual approach via a tribunal system and 17% wanted it to be based a small number of broader categories.

A further 30% favoured a hybrid of some of the options above. You can find the full results of the survey on our website.

One person responding to the survey spoke for many when they wrote: 'What figure can you put on a life? I'd pay a million pounds for it to go away and be normal like everyone else.'

There is a long way to go on the issue of compensation. We will be providing regular updates on this and other inquiry-related news throughout the year.

Keep up-to-date using our dedicated Twitter account at **@HaemoSocUK_PI** or join our private Facebook page.

The inquiry will examine a number of technical aspects of blood services in its oral hearings this spring.

It has already heard presentations on the history and organisation of blood transfusion services in the UK and has begun to take live evidence from former employees of these services.

The inquiry will also hear evidence about the fractionation plants at Elstree and Edinburgh as it looks in more detail at why government pledges to achieve self-sufficiency in blood products in the UK by the late 1970s failed to happen.

Hearings will probably take place for most of this year and are expected to finish with testimonies from those infected and affected by the contaminated blood scandal.

Coming up at the inquiry in 2022

January and February: blood services

February and March: blood transfusion policy and practice

March to April: self-sufficiency and domestic production by the Blood Products Laboratory (BPL) and Protein Fractionation Centre (PFC)

You are amazing

Thank you so much to all of you who have helped us raise money and make a difference to people affected by a bleeding disorder.

Your support means we can organise free events so that you can meet others and talk to experts, and offer specialised resources and advice when it's needed. It also allows us to advocate and campaign on your behalf for the best possible care, safe and effective treatment and equitable access for all.

If you'd like to raise some funds to support your community, here are a few ideas.

Ask your workplace

Could you nominate the Haemophilia Society as your workplace's Charity of the Year? Or suggest some volunteering, skills-sharing, pro bono projects, or corporate partnerships to support us?

Or how about a fundraising day? Anything from a simple cake sale, car wash or raffle, to organising a cross-department sports match or quiz night.

Join our lottery

Add excitement by joining our lottery, where everyone has an equal chance of winning up to £25,000, every week.

You can play for as little as £1 a week and all profits go directly towards funding our services for people with bleeding disorders. See our website: **haemophilia.org.uk/get-involved/give/**

Make something happen

Walk, run, talk, or don't talk! There are lots of ideas on our website to inspire you, as well as friends and family, in your fundraising.

If you don't fancy asking people for sponsorship you could hold an event and ask people to donate to take part, sell something that you've made, or hold a dress-down day in return for donations.

Our fundraisers Ash and Lina are here to help you make your activity a success, so please email **fundraising@haemophilia.org.uk**

In need of inspiration? Claire tells us why she kept walking.

"Alfie was 14 months old before we had a diagnosis of severe haemophilia A; mostly, it seems, because awareness and understanding about the possibility of haemophilia is just so low," says Claire, 40, from Wiltshire.

"When we were first told about Alfie's condition, one of our first thoughts was 'what isn't Alfie going to be able to do?'

"But we also got to speak to some of the Youth Ambassadors, who are all in their twenties and just living life and doing really well.

"One, Scott, had run a marathon, and another, Jess, was a teacher and spoke about the impact of bleeding disorders on women.

"They were inspirational and showed us that with support, Alfie will be able to do whatever he sets his mind to.

The newly diagnosed weekend was such an invaluable experience, and that's why we decided to raise money for the charity, so that more families who are on a similar journey to us can have the opportunity too.

"They were inspirational and showed us that with support, Alfie will be able to do whatever he sets his mind to."

But going to one of the charity's weekends for newly diagnosed families had such a positive impact on our outlook. We met other families going through the same experiences, which was fantastic.

"My husband and I walked 36km to represent the 36,000 people living in the UK with a bleeding disorder. It was the perfect day for walking around the stunning Wiltshire countryside, and the first 16 miles were great!

"It took from 9am until after 6pm at night, but we're so happy to have done it and we've raised £500.

"We're really pleased that through doing our walk and involving family and friends, we've helped people understand bleeding disorders that little bit more."

Glanzmann's: A Parent's Journey

When my son Felix was born he was covered from head to toe in bruises. At first doctors weren't sure why.

After 5 days of thorough tests at London's Great Ormond Street Hospital (GOSH), it was discovered that he had the bleeding disorder, Glanzmann's Thrombasthenia.

Glanzmann's, otherwise known as GT, is a rare, inherited blood clotting disorder, characterised by the impaired function of platelets.

It is one of the lesser known bleeding disorders and incurable. As such, there is no established regular treatment to keep the bleeds at bay.

In his first year I was incredibly worried about Felix as he bruised and bled so easily.

Kicking his legs in his pram, playing with toys, scratching himself and even crying could bring on bleeds and bruises.

After he reached one, he started getting nosebleeds. This was the real start of the journey.

It necessitated trips, often on a weekly basis and usually in the middle of the night to A & E for canula access medication.

Soon enough finding a vein proved troublesome and after harrowing scenes of trial and error it was decided he needed a port-a-cath for quick access.

"It is Felix who has picked me up on more challenging days, and happily tells strangers all about his medicine and care!"

I was incredibly nervous for Felix to have an operation but it had become necessary.

And despite the many bleeds, the nurses at GOSH taught me how to inject Novo7 (the best coagulating drug available) which has been a godsend to

have the control to stop bleeds and alleviate the trauma of the middle of the night hospital run.

Now Felix is 3, he has started nursery and wants to explore and play freely.

The staff have all been GOSH-educated and are terrific at supporting him. But there is a fine line between letting him try new things, yet not causing a bleed. My heart is always in my mouth when he falls!

There was no family history of bleeding disorders so it was a real shock to discover that he had GT.

At times I have felt scared, anxious and unsure.

Yet as Felix has learned to understand he has a bleeding disorder, it is he who has picked me up on more challenging days, and happily tells strangers all about his medicine and care!

Through all the injections, hospital stays and appointments he has become a confident and happy boy - and I have learnt more and more on how to handle his bleeding episodes.

In a bizarre twist of fate, I discovered a friend in America also has Glanzmann's.

There are only around 500 people in the world with the condition and doctors and family are completely amazed and baffled at how I could possibly know someone else with it, let alone be friends with them!

My friend is very positive, happy and lives an active life. We talk every day and she always listens knowingly to my many questions.

She has also given me so much hope that my son can still live a full and wonderful life, even with Glanzmann's as his constant opponent.

Article written by Annette Kellow, mum to Felix, 3.

Visit our website for fact sheets about some of the less common bleeding disorders, written by experts.

Wellbeing focus

"Actively looking after your wellbeing can be a really positive step, putting you in a more resilient place when life's inevitable curve balls come along, and helping you spot opportunities for making if there are changes that you want to make," says Dr Sarah Whitaker, a Clinical Psychologist who works across the Southern Haemophilia Network.

Sarah has shared these top six tips to help us all foster a sense of wellbeing.

Taking stock

Try and find regular times where you stop what you're doing and spend a moment checking in with how you are.

Notice your thoughts, physical sensations and feelings. What are you doing in response to these feelings? And is this helping you in the long-term?

Talk about it

Holding things in can sometimes feel a bit like a pressure cooker and so finding someone you can trust to open up to can be helpful.

A problem shared really can be a problem halved, and it can help you to feel less alone.

You could try talking to friends, family, a trusted member of your community, or a health care professional. The charities Mind and the Samaritans can also provide a listening ear.

If you are the one doing the listening or supporting, try not to jump in and attempt to solve any problems.

Being heard, and having your emotional needs validated, is often the most powerful experience.

Focus on one thing

Try and identify one small change that can help improve your wellbeing.

We can start with the foundations to good health; including safety, enough food and warmth. Then ask yourself if you are sleeping and eating well, getting some exercise and if you need help with your finances or relationships. It can

be easiest to take one small step, or change, at a time.

Seek help

If you have identified a change, find some help to make it happen. This needn't be a health care professional, although they can be good sources of support.

There are lots of self-help apps, websites or books to address areas such as sleep, healthy eating, and managing alcohol, and meditating and relaxation can also prove very beneficial to our wellbeing.

Sometimes partnering with another person can help you to stay motivated.

Life is a roller coaster

Change isn't straightforward, and there will be times when barriers get in the way.

Making some plans to deal with these barriers, means that you will be more able to adapt and get back on track again.

Keep a record

Sometimes it can be hard to remember the journey that you've been on. It can be helpful to keep a journal or blog to capture your successes and achievements, big or small, which can be a good reminder of how far you've come.

Haemophilia centres are increasingly taking steps to help people affected by a bleeding disorder to look after our minds, as well as our bodies, because we know that this is likely to improve health and wellbeing for the long-term. Many now have their own 'in-house' psychologists who work alongside haemophilia doctors, nurses and physiotherapists, offering various support and 'talking therapies' which help children, adults, individuals and families to cope at difficult times.

"If you or someone you know is feeling the strain, ask your haemophilia centre if they can refer you for support locally. Everyone needs someone who will listen and give them extra support throughout different times in their life."

"Everyone goes through times of stress and pressure, and we all deal with this differently," adds Sarah.

"But if you or someone you know is feeling the strain, ask your haemophilia centre if they can refer you for support locally.

"Everyone needs someone who will listen and give them extra support throughout different times in their life."

You can also find links to some helpful resources on our website at **haemophilia.org.uk/support/day-day-living/positive-mental-health/**

New women's bleeding symptom checker

We've launched an easy-to-use online symptom checker to help women and girls with heavy periods find out if they have a genetic bleeding disorder.

One in 5 women and girls who get medical help because of heavy periods will actually have a bleeding disorder, yet many outside our community are unaware they even exist.

The symptom checker, which is part of our Talking Red campaign that raises awareness about women's bleeding disorders, is designed to increase diagnoses and get women and girls the specialist treatment and care they need.

It is also aimed at women with a bleeding disorder in their family who may be putting up with symptoms they think are normal without realising they could get help in managing their condition.

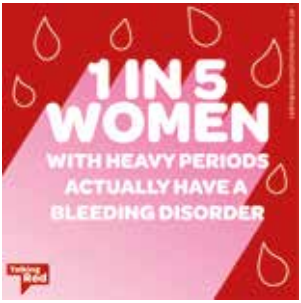
The online tool, which is supported by Takeda and LFB, only takes a few minutes to complete.

It guides the user through a series of questions about their symptoms and gives guidance and information so that if they do go on to visit their GP, they receive the right treatment.

To make sure the symptom checker tool reaches as many women as possible, we've run a high-profile campaign across our social media channels and beyond.

We're delighted that it has attracted a strong response.

You can help by sharing the symptom checker with your friends and family.



There are 17,000 women and girls in the UK living with a diagnosed bleeding disorder and at least another 35,000 undiagnosed – we hope that with our help more women can get the

right diagnosis and get help in managing their condition.

Sonya, 54, is one of five sisters who are all genetic carriers of haemophilia B as well as having a moderate form of it herself.

She had many bleeding incidents as a child, butthey were never investigated, despite her dad having haemophilia B. Sonya was only diagnosed aged 30, when she was pregnant with her first child.

She said: "There is a lack of understanding and awareness and it seems that too often from birth until they carry a child, women just haven't been offered specialist testing, even if they have a family history of bleeding disorders.

"If you have symptoms I would urge you to demand to have your factor levels checked at a haemophilia centre where they will have the expertise to diagnose you and support you, whatever your age."

Find the Talking Red symptom checker at: **TalkingRedSymptomChecker.co.uk**

Join us at Talking Red Live

On **5 March**, we'll be getting together in **York** for our first **Talking Red Live** since 2019.

Our free event for members is a chance to meet other women and girls with genetic bleeding disorders and find out about the latest in treatment and care from some of the leading clinicians in the bleeding disorders field.

Our speakers include Diana Mansour, Consultant in Community Gynaecology and Reproductive Health Care and Head of Sexual Health Services in Newcastle and Rezan Abdul-Kadir, Consultant Obstetrician and Gynaecologist with a special interest in bleeding disorders in London.

Book your free place here: **haemophilia.org.uk/events/events-calendar/talking-red-march-2022/**

A Life Inhabited

Thanks to advances in the treatments made available in the last few years, developing inhibitors isn't as worrying as it might have been a few years ago. Josh Crombie tells us about his journey.

Josh, 24, lives in Middlesbrough, North Yorkshire, where he's working for his local council.

"I have severe haemophilia A, and when I was 7 months old, I developed inhibitors. Because I was growing up without access to all the different types of treatment that we thankfully have today, my bleeds became difficult to treat. There were only two options open to me - one didn't work, and one only worked a bit!

"Limited treatment options meant I had to be very careful to do what I was told and sometimes I missed out, when the risks of activities didn't outweigh the benefits.

"At 7, I went on to FEIBA treatment, using a Hickman line. This was a big change and much more effective. The downside was that it was pretty inconvenient as a kid, but for the most part, it did its job, which came as a huge relief to my family.

"Then, at 19, I was offered the treatment Emicizumab, which has been life-changing. My old annual bleed rate was 50, but overnight it went to zero and I haven't had a bleed for 3 or 4 years.

"I inject into my thigh, stomach or arm under the skin once a week, though some people only have to use it once a month. Emicizumab works differently to replacing factor. In a way, it fools my body into accepting treatment.

"Changing my treatment has allowed me to do so much more and it's the best choice I have ever made with my treatment.

"It gave me the confidence to finish university, and made it possible for me to find work without the worrying I'd need to take lots of sick-leave.

"It's also made a big difference to my mental health. I can be much more positive, knowing that I'm ok and that my treatment is ok.

"Then, at 19, I was offered the treatment Emicizumab, which has been life-changing. My old annual bleed rate was 50, but overnight it went to zero and I haven't had a bleed for three or four years."

"I know that some people find under the skin injections uncomfortable, and prefer a standard needle but I couldn't be happier. I have a few scars, and some arthritis, but you'd barely know I have haemophilia.

"My mum still gets upset talking about my new treatment, as it's been such a transformation and made her so happy! After everything that we were going through before; never knowing if I'd run out of options. But now I have so much more confidence for the future.

"There's a phrase which says 'If you have an inhibitor, it's a life inhibited, not inhabited' and as a family, we struggled when I was younger. What I was allowed to do, or not, seemed very black and white and inflexible. But now, with the right treatment in place, you can find work-arounds to 'cheat' haemophilia, and give yourself the life that you want to live."

Inhibitor Facts

An inhibitor is a type of antibody that prevents factor replacement treatment from working, making bleeding more difficult to treat.

Inhibitors typically develop in the first 50 treatment days, with most developing in the first 20 days. This is why when people with severe haemophilia develop inhibitors it is usually during childhood, whilst people with mild or moderate conditions tend to develop them later in life.

Inhibitors affect around 30 per cent of people with severe haemophilia A, around 9 per cent of people with mild and moderate haemophilia A, about 3 per cent of people with haemophilia B, and only rarely people with other bleeding disorders.

Today, inhibitors are treated with immune tolerance induction (ITI) which involves regular exposure to factor treatment with the aim of the body becoming accustomed to the clotting factor. If this doesn't work then the new treatment Emicizumab, which mimics the role of factor VIII, allows people with haemophilia A and inhibitors to live a much more normal life with far fewer bleeds.

For further information, please visit our website **haemophilia.org.uk/bleeding-disorders/inhibitors/**

A whirlwind start

What a year! I've had the privilege of being your CE for just over 12 months, and there have been both highs and challenges.

The global pandemic has been the backdrop affecting us all, and as we emerge into a changed world, we are seizing the opportunity to look at the way we work; challenging our approach to supporting you, collaborating across the community, and finding new ways to generate income so that the organisation can thrive.

We've modernised our brand, including launching membership cards and improving our website.

We are redoubling efforts to support a national network of local groups, and are also strengthening collaborations; including renewing relationships with colleagues in other nations across the UK and signing new partnerships with Little Bleeders, Haemnet and the Hepatitis C Trust.

It's been exciting to finally be able to attend events, and the July and September weekends for our newly diagnosed families in Essex and Manchester were highlights.

It was a privilege to meet families face to face at last and hear their experiences. I could also see first-hand just how precious the opportunity was for many families to have the chance to chat to others who just 'get it.'

Like many of you, I have been following the infected blood inquiry closely and last year attended several, emotional hearings.

We will continue regular reporting from the inquiry and have responded to the on-going Compensation Framework Study after consulting with you, our members.

We have launched an innovative symptom checker for women with possible bleeding disorders and I'm looking forward to continuing to build momentum around this important campaign at Talking Red Live in March.

I hope to see many of you there, and at other events, in 2022. If you have any suggestions, I'd love to hear from you.

Fun times

Thank you everyone for keeping the home fires burning with your wonderful fundraising, despite difficult times. Here are just a couple of our members' having fun while they raise that cash!

Tom (13) and Luca (8), travelled from their Liverpool home to take part in the Big Red Bridge Walk London with their family.

Both boys have mild haemophilia A, and they were very keen to give something back after enjoying Youth Camp and making good friends with our Youth Ambassadors.

Never having tried any fundraising before, the family smashed their target and raised nearly £1,000!

Dad, Richard, says, "As parents, there were a number of great moments and we really did enjoy the day. Although Tom's face, when he saw the money raised on the JustGiving page – initially disbelief, quickly turning to pride - may well have topped the lot."

Kaye and her family from Coventry have been active fundraisers since son Ted was diagnosed with severe haemophilia A, aged nearly 3.

"Ted had lots of problems before his diagnosis, and we were always told that he had reactive arthritis. It was clear to see haemophilia wasn't really a well-known disorder.

"I even carried it all my life without knowing what it was! Then we were invited to a 'newly diagnosed weekend' and it was an amazing

experience. Seeing where donated money goes just makes us want to help, and so I started to run a football card most months on my Facebook which is very popular and sells within a few hours!

"Also, I work at ASDA, where 3 people have a close family member with a bleeding disorder. The store has been really great with fundraising and helping us raise awareness."

Of course, we also have to publically thank our Youth Ambassador **Matty, aka Buddy**, for traipsing around London as our mascot and causing quite a stir at our walk!

Dates for your diary

There's lots to look forward to this year, so be sure to register for events in plenty of time. Go to **haemophilia.org.uk** for details as well as the latest information on all events. Or you can email us at **info@haemophilia.org.uk** or telephone **020 7939 0780** for more information.

22 - 23 January
Gamechangers Challenge
Stay warm inside and get gaming.

17 February – 17 April
Race Around the World
How far will you go?

25 February
Bloody Good Brew
Is there a better excuse to stop and have a nice cuppa?

5 March
Talking Red Live, York
Our event to get talking about women with bleeding disorders.

17 April
36 Fitness Challenge
Celebrate World Haemophilia Day by getting physical.

24 – 26 June
Haemfest, Derbyshire
Entertaining camping weekend for everyone to get together.

1 – 3 July
Newly Diagnosed Weekend, Manchester

27 – 31 July
Youth Camp, Surrey
No parents allowed!

14 – 16 October
Newly Diagnosed Weekend, Essex