

# Community Matters

Autumn 2023

The  
Haemophilia  
Society



**More**  
Our latest news,  
events and  
updates

**Plus!**  
Youth Camp  
picture special

# Supporting each other

Inspiring, connecting and empowering people living with a  
bleeding disorder in the UK

# New merchandise has landed

We've got lots of exciting new arrivals in our online shop. Every purchase helps us keep our events free for our members and raise awareness about living with a bleeding disorder. Shop the full range using the QR code below or visit [haemophilia.org.uk](http://haemophilia.org.uk)



THS Shop



The Haemophilia Society Logo badge £4



Water bottle £10



Pen £2.50



Cap (limited availability) £15

You'll be excited to hear that we've also got new collection boxes! Contact our team at [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk) to find out more. •



Christmas cards now available!

T-shirt adult £9.50, child £7



# Proud to be by your side



Compiling this edition of Community Matters has been a fantastic opportunity to reflect on the inspiring and loyal support this charity is so lucky to enjoy.

I can't thank you enough for your donations, heroic fundraising efforts and words of encouragement which have kept us going in the difficult times we've all experienced in the last few years.

At last, it feels like we can look ahead with confidence, which is why I and the rest of the team are so excited to invite you to our largest event of the year – the Big Get-Together conference in Leeds on 18 November.

We've designed an event that not only brings together some of the UK's leading clinicians for updates and advice, but also gives you the chance to meet others in the

same situation to share experiences and learn from each other. I hope you can join us. You'll find the details of how to register on pages four and five.

We also look forward to the publication of the Infected Blood Inquiry's final report later this Autumn. There's a long way to go to secure full compensation and justice for all those infected and affected by contaminated blood products but rest assured that we will be by your side for as long as it takes, and beyond.

Kind regards,

Kate Burt  
Chief Executive

# Connecting Our Community

**We're so excited about seeing you all at our Big Get-Together for a weekend of friendship, fun and shared experiences in Leeds on 18-19 November.**

This year's conference at the Met Hotel brings together some of the UK's leading clinicians to discuss the latest in treatment and care for haemophilia, von Willebrand disorder (VWD) and other rare genetic bleeding disorders. Expect lively discussions, personal stories and workshops as we explore the issues that matter most to you.

Whether you want to know how to stay fit and healthy, find mental health support or get information about your treatment

options, we'll have it all at the Big Get-Together, which is free to our members.

For teens, there's a fantastic day-long workshop and we're pleased to offer an on-site creche for children aged 0-11 at a heavily subsidised rate.

Young or old, there's something for everyone with a bleeding disorder and their families.

Use the QR code to reserve your free place today or you can book through the events page on our website. •

## Join us for dinner and dancing

Our evening dinner and disco on 18 November promises to be great fun for the whole family.

Indulge in a delicious three-course meal with complimentary arrival drinks before letting loose on the dance floor in true Haemophilia Society conference tradition. The meal, which has vegan and vegetarian options, costs £35 for adults and £15 for children. Use the QR code to book your table or visit the events page on our website to make your reservation. •



## AGM open to all members

Our Annual General Meeting takes place at the Met Hotel in Leeds at 11am on 19 November and is open to all members. This year it will only be held in person and not online. Nominations for the Board of Trustees open in September and the results of the elections will be announced at the AGM. Audited income and expenditure results of the financial year 2022-23 will be presented, followed by a question and answer session. •



# Gene therapy update



**The first attempt to get a gene therapy for haemophilia B commissioned in the UK has been rejected by NICE, the government body tasked with reviewing the clinical and cost-effectiveness of new treatments for the NHS in England.**

At a NICE meeting in July all evidence about CSL Behring's product Hemgenix was considered, alongside submissions from the Haemophilia Society and our members. In addition, Ross Bennett and John Curley, who have haemophilia B, gave their views.

However, NICE decided that, at present, the treatment should not be prescribed on the NHS. This is likely to be for reasons of cost-effectiveness, compared to other treatments. There is also disagreement over how long the treatment will last for. NICE is currently reviewing this decision which may lead to a different outcome if there is a change in the product's price or more evidence to evaluate.

We were disappointed by this decision, as Hemgenix has been shown to be long-acting, potentially for a decade or more, and can substantially reduce the burden of treatment while still preventing bleeds at least as effectively as current treatments.

NICE has already begun consideration of another gene therapy for haemophilia B from Pfizer and a new longer lasting haemophilia A treatment from Sobi called Efanesoctocog Alfa (Altuviiiio). Both will be reviewed next year - as well as new treatments for people with haemophilia B with inhibitors. Consideration of all these treatments will also be taking place in Scotland and Wales. •

# Ed's gold rush

**Rower Ed Fuller has set his sights on winning gold at the 2024 Paralympics in Paris after overcoming significant joint damage to reach the top of his sport.**

Ed, 20, who was diagnosed with moderate haemophilia A aged two, is the World and European champion in the mixed coxed four and a key part of the British Para-Rowing team.

Although his clotting levels are 1.3%, Ed did not begin prophylaxis treatment until he was 11, following two bad ankle bleeds. He took up rowing the same year.

To become independent and progress in his sport, Ed had to overcome his 'huge needle phobia' to learn to self-infuse his factor treatment, aged 17.

Today Ed has restricted mobility and strength in his ankles but uses an adapted footboard in his boat which allows him to get into the correct rowing

position without putting tension through his ankles.

Ed trains full time with British Rowing three times a day, six or seven times a week. He treats himself with factor every other day or on consecutive days if necessary and receives expert physio support to keep his gruelling training schedule on track.

As a youngster, Ed was inspired by the fantastic achievements of Alex Dowsett, the professional cyclist with severe haemophilia. He said: 'If there's one child with haemophilia in the country that thinks of me in the way that I think of Alex then that would be incredible.' •

Meet Ed at our Big Get-Together in Leeds



Ed, front, in action

Photographer: Benedict Tufnell for British Rowing

# Surprise diagnosis hits three generations

**When Katy's toddler had his first heavy nosebleed, she never expected it to take more than a decade to find out that it was a symptom of a genetic bleeding disorder.**

Jaylen, who has a twin brother Shaylen and five other siblings, had numerous heavy nosebleeds throughout his childhood, often resulting in dashes to hospital or their GP's surgery to get help to stop the bleeding.

But it was not until earlier this year

that Jaylen, aged 13, was diagnosed with von Willebrand disorder (VWD), a condition the family knew nothing about. After more testing, they discovered that three generations were impacted, with Jaylen's younger sister, dad and nanny also diagnosed. Now Jaylen's wider family, including aunts, uncles and cousins, are also being checked.

Katy said: 'GPs kept telling me that it was 'just a nosebleed', but I knew it wasn't. I kept going back, but nobody would listen. Jaylen missed so many things in his childhood because of not knowing about VWD and it could have been diagnosed so much earlier.

'I felt like I was being paranoid, but now that we have the diagnosis it makes so much difference. Finally we're getting the support we need from our centre in Birmingham who are always available if I need advice. The most important thing is that Jaylen feels understood and is starting to come to terms with what's happened.'



## Compensation frustration as final report approaches



**The Infected Blood Inquiry will publish its final report later this Autumn, but there remains uncertainty about when the government will announce its decision on the payment of full compensation.**

Sir Brian Langstaff, Chair of the inquiry, had hoped that the government would already be well underway with a compensation scheme, as recommended in April in his second interim report, but ministers have made clear that no decisions will be made on this issue before the final report.

The inquiry reconvened for an unexpected week of hearings in July following frustration that the government

did not appear to be making progress towards a compensation framework. Prime Minister Rishi Sunak, Chancellor Jeremy Hunt and two other senior ministers gave evidence, but did not soften the government's position.

Acknowledging the 'appalling scandal' which the inquiry was set up to investigate, Mr Sunak said he was not prepared to give an 'artificial timeline' for compensation which would add to the 'litany of broken promises and dashed expectations' of the past. The inquiry was told that 50 meetings had taken place within government on this issue since the start of the year and that, by Whitehall standards, this was quick work.

Our Chief Executive, Kate Burt, criticised Mr Sunak for leaving those infected and affected 'in limbo' while we wait to hear when the final report will be published.

Contact us with any questions at [publicinquiry@haemophilia.org.uk](mailto:publicinquiry@haemophilia.org.uk)



# Youth Camp 2023

This summer we were joined by 45 children aged nine to 15 at our fantastic annual Youth Camp which took place near Derby. As you can see, it was a chance to make new friends and try some exciting activities. Thank you to our awesome volunteers who offered their time to give these young people wonderful experiences and very special memories. •



# Bossing it: Fundraising at work

**Fundraising in partnership with your employer can often produce generous donations at no cost to yourself.**

It can also start conversations with colleagues about the reality of living with a bleeding disorder.

Many firms offer match-funding, Charity of the Month/Year nominations or payroll giving incentives to their employees. Does yours?

Our fundraising team would love to support you in approaching your employer to tell them about the work of our charity.

## Hannah

Hannah, who works for the Bank of Ireland, raised £450 by nominating us for a payment from the company's 'Begin Together Fund' which gives donations four times a year to charities close to their employees hearts. Hannah's two sons Charlie, aged two and Noah, aged one, have severe haemophilia B. •



Scott McLean, our Corporate Partner and Major Donor Fundraiser, said: 'Fundraising in your workplace is an opportunity to give without giving. Often companies will have pots of money set aside for community or charitable use, but employees don't always know about them. Raising money at work helps us fund events such as Youth Camp and Newly Diagnosed Weekends as well as education materials, which are all free to our members.'

Contact Scott at [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk) for more information. •

### Ask your boss about:

- Payroll Giving Scheme
- Match-funding charity fundraising
- Hosting a fundraising event
- Nominating the Haemophilia Society as your firm's Charity of the Year
- Volunteering days

## Craig's Charity of the Year

Craig Wheeler raised more than £11,000 for the Haemophilia Society after naming us as his Charity of the Year when he became the local Mayor.

As the incoming Mayor of Thrapston, which is near Kettering, Craig was invited to nominate a charity close to his heart to benefit from a series of fundraising events during his 12 months in office.

Craig and his wife Lauren chose our charity because their son Arthur, aged five, has severe haemophilia B as well as other platelet disorders.

After an action-packed fundraising year, including holding an Abba night, a Quiz and Chips event and a Coronation celebration, Craig, his family and the people of Thrapston raised an incredible £11,000.

Craig said: 'I feel satisfaction, gratitude and a degree of relief that everything we planned came off so well. With the Haemophilia Society, you can see where the money is going and the direct benefit that all the funds raised have for members and the community. That is very important to me and my family.' •



Craig and Scott

## Double your fundraising results

Having a sympathetic employer can really boost your fundraising, as Emma discovered when her firm doubled her donation to the Haemophilia Society.

Emma, whose brother Scott has severe haemophilia A, raised £264 by holding a cake sale at her office on World Haemophilia Day and then a further £1,140 as part of a work team to take on the Three Peaks Challenge. Their employer, the medical diagnostic firm Sysmex UK, agreed to match-fund the amount, increasing the total to a fantastic £2,800.

Keith Howes, managing director of Sysmex, believes good deeds should be 'encouraged and recognised'. He said: 'So when our staff give up a day to bake cakes to sell or a weekend to scale the three peaks, it's right that the company puts its hand in its pocket to recognise and celebrate their achievement, by matching pound for pound what our colleagues have raised, and we're happy to do so'. •



# The future is bright

**We're excited to introduce three new members of our Youth Ambassador family who will offer mentoring and support to young people with a genetic bleeding disorder.**

The new Youth Ambassadors (YAs) are Emily, who has severe haemophilia A, Zaynab who has a factor VII deficiency and Peta, who lives with a mild unclassified bleeding disorder.

Peta is passionate about participating in sport and determined to demonstrate that 'my diagnosis is not a disability'. Emily and Zaynab hope to offer support to girls with a bleeding disorder, and all three are looking forward to meeting you, our members, at our upcoming events.

Our YA programme, which was launched in 2015, encourages and empowers our young members to develop the skills to become our future

leaders and advocates. To ensure the programme continues to grow and increase its impact, we've launched a Youth Board, made up of six senior YAs.

Chaired by Ross Bennett, who has severe haemophilia B, the Youth Board wants to bring a fresh perspective to the Haemophilia Society and will ensure that our strategies and initiatives are relevant, inclusive and responsive to the needs of young people within our community.

The board's first project is to put together a short video about the transition between paediatric and adult treatment and care services which will be launched later this year. •



Emily



Zaynab



Peta

# First steps towards self-treatment

**Learning to self-infuse is a milestone for anyone who relies on intravenous treatment to manage their bleeding disorder.**

Andrew, 13, who has moderate haemophilia A, overcame the mental and physical hurdles to self-injecting and is now starting to treat himself with Elocta every three days.

It's been a gradual process which began three years ago when his treatment switched from on demand to prophylaxis and Emma, Andrew's mum, was trained to treat him.

Initially Emma found it stressful to give the injections, but, with the support of their centre in Manchester, they developed a system which slowly encouraged Andrew to take a more active role in his treatment.

This is how Andrew progressed to self-infusion:

- Inputting his treatment into Haemtrack
- Using breath-work to keep calm
- Deciding when he was ready for the injection from his mum
- Preparing his treatment
- Giving the infusion, once his mum had put the needle in place
- Taking the needle out

- Looking at the needle in his arm
- Watching the needle going into his arm

Emma said: 'The first time he didn't quite find the vein, but he overcame the biggest hurdle which was actually putting the needle into himself, so we were all very proud.'

Learning to self-infuse is an important step towards independence for Andrew. He said: 'I'm more confident with it now. I don't find it a scary experience anymore, it's just something that I have to do.' •



# Sharing experiences globally

## Bonnie's a European ambassador

Congratulations to Bonnie Taylor who has become an ambassador for women with a bleeding disorder for the European Haemophilia Consortium (EHC).



Bonnie, who has severe haemophilia A, said: 'It is so important that we change the way medical professionals diagnose and treat women. Coming together is important to achieve this and let other women know they are not alone.'

The World Federation of Hemophilia (WFH) has organised a free online Global Summit on Women and Girls with Bleeding Disorders on 28-29 September 2023 which is open to anyone with a bleeding disorder. More details on WFH's website. •



## First Glanzmann Thrombasthenia conference

Amy Owen-Wyrd, a member of our board of trustees, was a speaker at the first ever conference dedicated to the rare bleeding disorder Glanzmann Thrombasthenia (GT) which was held in Boston this summer.

As a mental health nurse whose son Logan has GT, Amy was uniquely qualified to give a presentation on the psychological impact of living with the bleeding disorder, which covered topics such as depression and denial as well as looking at relationships.

The conference was organised by the US-based Glanzmann's Research Foundation. Amy said: 'You can't have good physical health without

good mental health. I was glad to have the chance to be part of the conference and give my presentation, which lots of people told me resonated with their experiences.' •

# Major new project on women's treatment and care

Women and girls now make up the majority of people in the UK with a diagnosed bleeding disorder.

However, women are far more likely to be diagnosed as adults and studies show that on average women with bleeding disorders are diagnosed 10 years later than men. The quality of specialist care for women and girls varies considerably across the UK.

We believe outcomes and standards of care should be better, which is why we are launching the SACRed Project to improve access to treatment and care for women and girls with bleeding disorders.

This project will use existing studies, submitted evidence, focus groups, surveys and centre visits to map the current care landscape and set out ways in which it can be improved.

We are looking for evidence from women and girls with bleeding disorders, their families, healthcare professionals, NHS and any other stakeholders to help inform this report, which will be published next year. To submit your stories and other evidence or sign up to be part of the project, visit [haemophilia.org.uk/SACRedProject](http://haemophilia.org.uk/SACRedProject) or email [jeff@haemophilia.org.uk](mailto:jeff@haemophilia.org.uk)

We are grateful to Octapharma, LFB, Sobi, Takeda and Roche who have sponsored this project. •

**Talking Red**

Talking Red is our campaign which raises awareness and offers support to women and girls with a bleeding disorder. Find out more at [haemophilia.org.uk/support/talking-red](http://haemophilia.org.uk/support/talking-red)



Picture from Talking Red Live 2023

# Thank you for your amazing support!

We are always blown away by the dedication you show in raising money and awareness about the work that we do. Thanks to your donations and fundraising, we are proud to say that all

our events continue to be free to our members and we can work in support of better treatment and care for everyone with a bleeding disorder. Small or large, every donation helps. Thank you!

## Jacob the superstar fundraiser

Seven-year-old Jacob enlisted his friends, schoolmates, teachers, footie pals and fellow members of the Lincolnshire and East Midlands local haemophilia group, to raise £1,400 during a sponsored walk.

After attending our HaemFest camping weekend in Derbyshire, Jacob wanted to raise money to ensure the event could take place again and encouraged 60 people to join him on the walk along a stretch of the coast near Skegness. What an achievement! •



Jacob, right, with his friend Joshua

## Marathon runners raise record total

Our 13 London Marathon runners raised a whopping £40,000 – the largest amount ever from



this event. We're really grateful to everyone who trained so hard to take part for us. Special mention has to go to Andreea, pictured, whose son

has haemophilia, who raised an astonishing £12,000 for us and is already planning to do it all again after getting a ballot place to run in the 2024 event. Our runners for next year have already been selected but if you have a place in the London Marathon and would like to raise money for us please get in touch. •

## Joey's triple fundraising inspirations

Three very special people with bleeding disorders inspired Joey Beavis' insane fundraising challenge of walking 100km non-stop across the Peak District in 17 hours which has raised more than £2,200 for our charity.



Joey, Lauren and their family

Joey's motivation comes from his son Max, 18 months, and his wife Lauren who both have type 2 von Willebrand disorder. Max had a brain bleed at birth but has thankfully made a full recovery. Joey also wanted to raise money in memory of his uncle, David Hatton, who died as a result of treatment with contaminated blood products in 1998.

Joey said: 'My clients, family and friends all know about Max and his traumatic start in life and they've been so generous in supporting me. I feel honoured to have done it for the Haemophilia Society.' •

Got a question about fundraising? Email us at [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)

## Archie puts haemophilia centre stage

Alex Clark has raised more than £50,000 for the Haemophilia Society since his son Archie, now 13, was diagnosed with severe haemophilia. Alex launched his golf event 'Archie's Cup' more than 10 years ago in his home county of Hertfordshire and, thanks to his generous friends and colleagues, it's become a legendary fundraising event. Plans are already underway for Archie's Cup 2024, which takes place next July. Archie is pictured with the cup below.

Alex said: 'Archie's Cup is my son's favourite day of the year, he enjoys everyone coming together. He's not always had a great time of it, but this is something positive I can do to raise money and put haemophilia centre stage for a day.' •



# Dates for your diary

Go to [haemophilia.org.uk](https://haemophilia.org.uk) for details as well as the latest information on all events. Or you can email us at [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk) or telephone **020 7939 0780** for more information.

**28 – 29 September, online**

**Global Summit on Women and Girls with Bleeding Disorders**

Free online event organised by the World Hemophilia Federation (WFH). The theme is equity and access.

**28 October, London**

**Service of Remembrance and Thanksgiving**

For those infected and affected by the contaminated blood scandal.

**18 – 19 November, Leeds**

**The Big Get-Together**

Our conference for everyone with a bleeding disorder.

**18 November, Leeds**

**The Big Get-Together Dinner and Disco**

Join us for a delicious meal after the day's conference events.

**19 November, Leeds**

**Annual General Meeting**

Open to all members.

**6 December, London**

**Christmas Carol Service**

Enjoy an uplifting service and beautiful singing from the choir at St Botolph's Church.

## 2024

**2 March, Leicester**

**Talking Red Live**

For women and girls with a genetic bleeding disorder and those who support them.

**21 April, London**

**London Marathon**

Cheer on our fantastic runners.

**17 – 19 May, Milton Keynes**

**Newly Diagnosed Weekend**

Support for young families.

**24 – 28 July, Staffordshire**

**Youth Camp**

For children with a bleeding disorder and their siblings aged nine to 15.



HaemFest 2023

**The  
Haemophilia  
Society**

[haemophilia.org.uk](https://haemophilia.org.uk)

[info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)

020 7939 0780

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