Community Matters

Spring 2023

The Haemophilia Society

Join Race Around the World

Time to get moving

Could you be a virtual volunteer?

We are often approached by individuals and companies who are conducting research which may benefit people with bleeding disorders in the future. Consequently, it would be fantastic to build a volunteer bank of members – all disorders and parents too - who are willing to give their opinions and share experiences. Could this be you?

If you can help, we will occasionally email you with opportunities to participate in research by vetted third parties or from the Haemophilia Society (THS) itself, usually conducted virtually or by phone. You won't be bombarded, and you can choose to participate or not with each individual request. You would be acting as an invaluable sounding board for the community, and for some research a small token of appreciation is offered too!

Please contact Debra if you are interested at **info@haemophilia.org.uk** •

LGBTQ+

Mark Ward is our LGBTQ+ Ambassador. He has been an active member of THS for more than 25 years, raising awareness about living with HIV, equality and diversity, as well as campaigning for justice for those infected by the contaminated blood scandal.

'For the LGBTQ+ community, recognition is vital. We need to be seen and heard. At the moment there is still too much stigma associated with our community, and we are still not getting parity of treatment,' says Mark.

'I am here to be a voice for the LGBTQ+ community, and to assure you that the Haemophilia Society will support you and whoever you want to be. It can be very difficult growing up without any positive role models and it can leave you feeling even more isolated. Please know that I am here to represent and support you.'

If you'd like to contact Mark in complete confidence, for a chat or advice, please email him at **mark@haemophilia.org.uk**

You can also buy LGBTQ+ pin badges at our online shop to show your support. •

Getting moving with Alex Dowsett's Little Bleeders

We are excited to have entered a new partnership with the charity Little Bleeders, which supports young people with bleeding disorders to 'move more and be more'. It was set up by professional cyclist Alex Dowsett, who has severe haemophilia (pictured below).

Little Bleeders fundraises to support more children with bleeding disorders to have access to sport and physical activity through grants. It also raises awareness by educating schools, clubs and coaches about children with bleeding disorders and the importance of allowing them to safely participate in sport. There are many ways that we will be working together to achieve these aims in the next few years.

Our partnership in year one includes Alex and his wife Chanel running as part of our 15-person strong London marathon team this year – what an inspiration! •

Von Willebrand's Day Success

It was fantastic to see lots of new faces at our Von Willebrand Disorder Day at the end of January. Many thanks to our speakers, who were terrific; the dentistry talk was especially useful.

We're proud that we consistently get good feedback about our events, so why not join one this year? •

Gene therapy news

A gene therapy for haemophilia B is expected to be licensed soon.

Etranacogene Dezaparvovec (Hemgenix), a product developed by Uniqure and marketed by CSL Behring has received a positive opinion from European regulators and should get a UK license soon.

We are already working with NHS England and NICE and making submissions for a meeting in July 2023 where NICE will decide whether they will recommend it for use in the NHS in England.

It is difficult to make the case for expensive new treatments, and a gene therapy for haemophilia B, as very long-acting treatment, that might work for decades, comes with a lot of uncertainty. However, while there are already effective treatments for managing haemophilia B, substantial unmet need remains, for some people treatment outcomes long-term are not great, and there is a heavy burden of treatment.

People with haemophilia also tell us of the anxiety and worry in managing their condition and how they avoid certain activities and situations. This treatment may offer a good alternative (and other companies have gene therapies for both A and B in trials which may be licensed in the future).

We have a working group for people with haemophilia B or parents of children with haemophilia B to help us make the case new treatments and for other improvements in care. If you would like to be involved, please email **jeff@haemophilia.org.uk** •

‘The inquiry has brought people together’

As the Infected Blood Inquiry’s hearings close, two of our members, Helen and Howard, consider the impact the inquiry has had on their lives and what they hope it will achieve.

Helen says, ‘When the inquiry was announced in 2017 it gave my husband Michael a real lift. He had been infected with hepatitis C through treatment for his mild haemophilia, and had campaigned for many years for an explanation of what went wrong. We noticed that once the inquiry started, our friends and family started to take what we’d been telling them more seriously – they couldn’t believe how much people had suffered.

‘I don’t think I’ve ever cried as much as I did during the first witness hearings in 2019. We’d also just heard that Michael needed more tests and later that year he was diagnosed with liver cancer. He died in June 2021. Attending the inquiry alone is really sad, but I need to do it for him. Michael wanted to know what really happened – he never believed it was ‘inevitable’. I hope the inquiry and Sir Brian Langstaff will finally provide those answers.’

Howard, above, says, ‘Attending the inquiry for the first time in Leeds in 2019, it really hit me how much infected blood products and blood transfusions had crushed the lives of such a wide-reaching and diverse group of people.

‘That poignant experience made me want to get more engaged, as the scandal has always felt part of my wider haemophilia story. The inquiry has opened up conversations which have perhaps never happened before, outside close family, and brought people together through shared experiences. I hope the final report will, for the first time, give a clear, comprehensive picture setting out what happened – specifically when and how.’ •

A letter to our members

Kate Burt, our Chief Executive, and Clive Smith, our Chair, reflect on the last four years of evidence at the Infected Blood Inquiry and look to the future.

Dear Members

It seems hard to believe that the Infected Blood Inquiry is almost over. After four years of evidence, some of it deeply personal and harrowing, we now await the final report in the autumn from Sir Brian Langstaff, Chair of the inquiry.

Expectations are high. Sir Brian and his team have conducted their investigation with compassion, sensitivity and integrity. We have great confidence that the truth will be uncovered.

The immense suffering caused by this avoidable treatment disaster has been deepened by decades of denial from successive governments. Evidence to the inquiry clearly shows that many infections and deaths could have been prevented if government had responded more quickly to known risks in blood and blood products used in the 1970s and 80s.

Government must address the mistakes of the past by acknowledging what went wrong and committing to full compensation to those infected and their families.

While Sir Brian's report will mark an important moment in the long fight for justice, there is a lot of work ahead. We are continuing to lobby government to produce a workable compensation framework in partnership with our community and ensure it is ready to implement as soon as possible.

The inquiry has brought with it both relief and burden as experiences are shared and traumatic experiences re-lived. We want to reassure you that we are here to support you and will remain at your side for as long as you need us. •

Clive Kate

Inquiry to issue report on compensation

Sir Brian Langstaff, Chair of the Infected Blood Inquiry, will produce an interim report about a framework for compensation before Easter 2023.

Speaking as the inquiry's public hearings ended on 3 February, Sir Brian also announced that his final report would not be published before autumn 2023, but assured everyone that he would write it as quickly as 'reasonable thoroughness' permits. He said: 'Time is not a luxury I can squander.'

In July 2022 Sir Brian published an interim report which resulted in the payment of interim compensation to those registered on a UK support scheme. His second report is likely to look at recommendations made in a report on compensation to the government by Sir Robert Francis KC last year.

Announced in July 2017 by Prime Minister Theresa May, the inquiry has sat for 286 days and listened to oral evidence from 370 witnesses, including those impacted by contaminated blood products, clinicians, civil servants and politicians. It has received 4,034 statements from infected and affected people.

More than 300 people attended the final day of the inquiry at Aldwych House in London. The packed hearing room rose to its feet when Sir Brian entered for the last time. He said: 'I thank you with sincere appreciation for making this a collective endeavour, for the warmth with which you support one another, and for your kind words about the inquiry team and its process. Thank you all, individually and collectively. Thank you and goodbye, for now.' •

Thank you

Huge thanks to all of you who raise or donate money to allow THS to continue to make a positive difference to the bleeding disorders community. Here's a snapshot of your fantastic efforts.

For the last eight years, supporter Rhi has challenged herself to wear a different Christmas jumper every day from 1 – 25 December. Rhi has used this challenge for the last four years to raise money for THS, because of the support given to her best friend and her four-year-old son who has haemophilia, as he 'navigates the rest of his life with this superpower'.

This year Rhi raised an amazing £1,060 with her Jumperathon, thank you so much!

Helen is an actress in London's West End. Her twin brother has haemophilia, and Helen carries the gene. Helen says that the disorder very much affected their childhood, and that her brother has overcome a great deal.

Helen will be running the London Marathon for us in April, but in the meantime, she held a cake sale (right) and collection at the theatre which raised a fabulous £2,300. Well done, Helen, and good luck for the marathon!

Craig Wheeler is the Mayor of Thrapston, near Kettering, and he has chosen THS as his Mayor's Charity of the Year because his family wanted to give something back after they found our newly diagnosed weekend so helpful. Craig's youngest son, Arthur, has severe haemophilia B, as well as platelet disorders.

Craig and his family have raised an incredible £7,500 so far with events like a 'Party in the Park' and firework displays. Thank you, Craig, and Thrapston! •

Race Around the World needs you!

Join us to raise funds for the bleeding disorders community one step at a time.

Please join us to race virtually around the world. The goal is to collectively cover the 38,100 miles in 60 days from 17 February to 17 April, which is World Haemophilia Day. By asking your family, colleagues and friends if they are able to make a donation or sponsor your contribution to the race, you will make a positive difference to the bleeding disorders community in the UK. It's also another great reason to keep active, and we know that healthy bodies bleed less.

You don't have to walk or run, any physical activity from yoga to dancing can be logged against the 38,100-mile journey. You'll find out more on our sign-up page, as well as promotional materials to help share what you are doing and why.

When all our miles are added together, by 17 April, we will have virtually circled the globe, made new friends, got fitter, and raised lots of money too!

If you'd rather watch...

Please sponsor our head office team instead! We have pledged to cover 5,000 miles. That's a tall order for 14 members of staff, so please sponsor us to make it worthwhile!

Any amount can make a difference, for example, £20 buys art materials for our creativity tent for Haemfest or £60 can pay for one young person to enjoy one fitness activity at Youth Camp.•

Sign-up at
haemophilia.org.uk/ratw
or you can make a donation at
justgiving.com/campaign/RaceAroundTheWorld2023

New knee, new ambitions

After decades of severe joint problems, Neil Weller braved a complex mega-knee replacement in a 'last roll of the dice' to save his leg.

Surgeons told him that a highly-specialised procedure to completely replace his right knee and surrounding bone with a custom-made joint was his final option after experiencing major mobility problems following persistent infections and three failed knee replacements.

Neil, 51, (pictured with his son) who has severe haemophilia A, agreed to the surgery hoping it would give him a second chance to achieve his dreams, such as perhaps one day walking his daughters down the aisle.

He had his first knee replacement at 35 but has had debilitating problems with his right knee ever since. Neil said: 'It was like being in an escape room, cracking the code and then finding yourself in yet another escape room. Dealing with the pain and disappointment of yet another failed operation was really hard, but you have to keep going.'

The plan for his new knee was devised by Abtin Alvand, Consultant Orthopaedic Surgeon with a special interest in knee revision surgery at the Nuffield Orthopaedic Centre in Oxford. He worked

with Neil's haemophilia team as well as specialists in plastic surgery and infectious diseases. Neil's new joint is about five times bigger than a first knee replacement to compensate for the bone he's lost through infection and previous operations.

In the first procedure, which took nine-and-a-half hours, Neil's knee and scar tissue were removed and a metal rod inserted in the gap, which was packed with antibiotic loaded cement. Muscle from Neil's back was removed and attached to his upper leg, forming a 'flap' to cover his new knee. Factor cover was needed three times during the operation.

After 22 days in hospital to ensure there was no infection and the skin graft had worked, phase two involved slotting in a bespoke prosthetic knee joint and covering it with the grafted skin flap. The operations were a success. Neil's knee now has a 110 ° bend where previously it was 45 °.

Mr Alvand said: 'Neil's knee has got an excellent range of movement and is infection-free. He's in good shape and I'm very pleased with the outcome. A procedure like this, which has only been done a handful of times in the UK on someone with haemophilia, needs a large multi-disciplinary team of specialists.'

It's been a long haul, but after 11 procedures to his right knee involving 74 nights in hospital over more than two decades, Neil is positive about the future.

Neil said: 'Words fail me when I think about what my surgeon, Mr Alvand, and the medical team have done for me. I've been given an opportunity that a lot of people with haemophilia haven't had, because they're no longer with us. I was determined to stand up in my kitchen and cook again, and I intend to play golf and ride a bike. That was the brief, and they stepped up to the mark.' •

Speaking up for equal treatment

When Muhammed remembers his son growing up, he wishes he'd had a louder voice when it came to ensuring that his son received the best treatment and care for his bleeding disorder.

But as a young father grappling with the shock of a haemophilia diagnosis and unaccustomed to medical terminology, he felt at a disadvantage from the start.

Muhammed said: 'There can be quite a stigma to having a bleeding disorder in some communities and even in the medical profession itself, and therefore accessing the right healthcare can be very challenging and I recall there were many incidents when we experienced poor healthcare and little or no support.'

Muhammed's son, who was born in the 1970s, experienced unexplained bleeds as a baby, but despite numerous trips to their local GP and hospitals, he was not diagnosed with haemophilia until he was six years old and up until then he suffered with bleeds, aches and pains which sometimes meant multiple visits to the GP and hospital.

After the diagnosis, Muhammed feels that his son was sometimes given a very good level of care and he pays tribute to those particular doctors and nurses, but overall, he and his family believe the medical care needed to be better and that there could have been more support and information about the condition, including counselling.

Muhammed's family were devastated when his son died aged 44. Muhammed said: 'I feel my son did not get the support he needed, and he and my family were let down by some within the medical profession. I don't want anyone else affected by haemophilia to go through the same experience we had, which is why I would like to help in whatever way I can to help others get the individual support which is right for them, especially those with a South Asian heritage.'

Muhammed adds that his son and the family got great support from the Haemophilia Society and pays tribute to some of the staff and volunteers past

‘There can be quite a stigma to having a bleeding disorder in some communities…accessing the right healthcare can be very challenging.’

and present. Last year Muhammed and eight members of his family took part in our London Bridge Walk (right) to raise money and awareness about living with a bleeding disorder.

However, he believes more needs to be done to meet the needs of our changing society.

Sunny Maini, our Von Willebrand Disorder Ambassador, agrees. Sunny, who was diagnosed with severe VWD Type 3 as a boy, said: ‘My parents struggled to grasp what the condition meant, and how to manage it. It wasn’t something that they wanted to talk about or discuss publicly and I didn’t know anyone else with the condition who I could talk to. Coming from an Indian background, there was a lot of stigma associated with my condition, and it was kept hidden as much as possible.’

‘I hope the more that people from different backgrounds speak openly about their experiences of living with bleeding disorders, the less isolated people will feel. I hope they will feel more empowered to be able to ask for more support.’

To talk to Muhammed or Sunny about your experiences, please contact them through our office on **0207 939 0780.** •

‘I have learnt that with planning, anything is possible for my son. Hearing that Youth Ambassador Ross went to a jungle for a few months blew my mind. I was worried my son’s life would be restricted. I no longer feel this, and this is thanks to Ross.’

Attendee at a Newly Diagnosed Weekend in Brentwood last year.

THS is a charity. Thanks to the generosity of people like you, we are able to offer all our unique events and specialised information for free, meaning that no-one is excluded from the support that they deserve on financial grounds.

If you wish to make a donation towards this work, contact us on **020 7939 0780** or visit **haemophilia.org.uk/donate.** Thank you.

Getting to know you better

This article is about data – but please keep reading! We are asking for just five minutes of your time.

Data might not set your pulse racing, but to us as an organisation, accurate data about our members is priceless. Accurate data means that we can tell you about events near to you, contact you with news that's relevant to your disorder, put you in touch with others with similar issues, and much more. However, inaccurate and/or incomplete data means we can't contact you about the important stuff, and what interests you, in the most efficient way.

This is where we are asking for your help. Please take just five minutes to complete a Member Update form so that we can validate and update the data that we currently hold for you. Your completed forms will make our records much more accurate and comprehensive. For example, currently we are missing a valid postal address for 4% of members, and have no email address for just over a quarter of members. We would really appreciate your help to put this straight.

Please download the Member Update form at **haemophilia.org.uk/member-update** which you can then email back to us at **info@haemophilia.org.uk.**

Alternatively, if you prefer, we can post you a form to complete. We can also update your information over the phone, so please call **020 7939 0780** if that's easiest.

Of course, please be assured that we comply with all legislation and best practice principles to store the information that you share with us. If you'd like further information, or have any questions, please contact us at **info@haemophilia.org.uk**. •

Teen Travel

It can be a big step when a young person makes their first trip alone, so we asked one mum to share her experiences, and one keen traveller to share some tips.

Anne is a teaching assistant in North Yorkshire and mum to 17-year-old triplets, all with moderate haemophilia A (pictured below with her family).

When the boys were younger, at residential trips in the UK, Anne would stay nearby to be able to give them their treatment. But then at secondary school a trip to Belgium came up, and one of the boys, Sean, then 13, was really keen to go. It meant being away for three nights, and he would need to independently give himself a treatment while he was away.

Anne explains, 'We gave it a lot of thought. Of course, as a parent you worry, and stupid ideas come into your head, but you also want them to go. We discussed it with our haemophilia centre, and they said that, with training, they would try to make it happen. We also met-up with the school to make sure that they were happy with Sean looking after his treatment and what it would involve.

'Sean really wanted to go, and you have to try and find the balance between worry and opportunity. I tried to rationalise things and I did my best to mask my worry. We also gave ourselves plenty of time to prepare, so that everything was in place for Sean to feel

confident that he could manage when he was away. In the end, it went really well, and it actually gave all the boys a boost and prompted the others to gain independence with their treatment too.

‘I’m more inclined to wrap the boys up in cotton wool, while my husband is more relaxed. But at the end of the day, we want them to have opportunities, and not restrict them.’

‘I’ll still worry, especially as the next step will probably be going on holiday with friends. Plus, now they are 17, the next concern is them getting into a driving seat! But you have to let them live their lives.’

Alex, 27, is a THS Youth Ambassador, and he and his twin brother have travelled all over the world.

He says, ‘For travel abroad, first check plans with your haemophilia centre. Ask your nurse to write a letter for customs explaining items you need to carry, like sharps. In Europe I’ve not had any problems, but in other places officials can be more intrusive, so it’s good to be able to tell them to call the number on the official letter. Clearly label all your medicine and supplies, and keep them with you as hand luggage, taking extra in case of delays.’

It’s also important to research the nearest haemophilia centre to the destination, in case of difficulties. Reassuringly, Alex says that he’s never actually had to go to a centre overseas, but it’s vital to know where to find help if you need it. Comprehensive travel insurance is another essential back-up plan – see our website for further information at **haemophilia.org.uk/support/day-day-living/travel/**

Alex ends, ‘Just prepare thoroughly before going anywhere. For us, as long as we had treatment and could self-inject, my mum became much more relaxed. At that point we’re really no different to anyone else and we haven’t looked back.’ •

Being rarer than rare

Kimberley, 34, has the rare bleeding disorder dysfibrinogenemia, as does her young daughter Eleanor.

Kimberley is a trained nurse, which gives her a good background to understand her condition, but she often finds that bleeding disorders are not well understood in a clinical setting, even at a senior level, unless that person is actually a specialist.

'It's not the fault of medical staff,' explains Kimberley, from Glasgow. 'Staff need to be better supported with more training around bleeding disorders. There also needs to be a better multi-disciplinary approach, with everyone talking to the haematologist, because people with bleeding disorders can present with an unrelated condition but there is so much crossover in care when you see someone with a bleeding disorder.'

When she was a child Kimberley remembers bruising quite easily, but she had her tonsils removed without any problems. It was only when her condition showed-up in quite general tests when she was in her mid-20's that she was diagnosed and other symptoms began to make sense, especially around her periods.

'I was always so worried about blood soaking through my clothes, it was quite embarrassing and I wouldn't want to go out or dare to sit in someone else's car. It would just be a dreadful blood-bath each time.'

Yet Kimberly found that her heavy period symptoms were dismissed, with doctors telling her 'that's just how periods are' and not treating the issue seriously.

'When I was diagnosed, I was completely in shock,

‘You don’t want to be the odd one out, and others find it hard to understand.’

and quite anxious as I didn’t know anything about dysfibrinogenemia. I had to get in a routine and get to grips with it to be able to live a normal life. Even for minor procedures I now take tranexamic acid before and afterwards, and sometimes fibrinogen too. But it’s annoying to always have to remember to take it with you. You don’t want to be the odd one out, and others find it hard to understand.

‘Because of my medical training I might be able to understand what’s going on more than some people for whom a diagnosis comes out of the blue, and I wonder how well I would cope. Even if you just have a cold there are medications that you can’t take. It must be even more difficult trying to explain something to other people that you don’t understand very well yourself.’

‘I only know one other person with my condition in the UK, and one in New York! It’s a godsend to be in touch with them, for someone else to really get it, and to be able to message them.

‘It’s important to remember that you’re not alone, and you can live a relatively normal life, if you educate yourself and others. I remember one doctor I saw who admitted that they didn’t know that much about bleeding disorders or my condition, but they said that they would go away and learn. That was really positive.’ •

You are not alone. If you are a woman or girl with a bleeding disorder, or a family member of someone who does, join us at Talking Red Live in Oxford on 4 March, where you can meet with others who understand and share your experiences.

haemophilia.org.uk/talkingred

Dates for your diary

Visit haemophilia.org.uk for full details as well as the latest information on all events. Or email us at **info@haemophilia.org.uk** or telephone **020 7939 0780** for more information.

17 February
Start of Race Around the World
Add your miles to our fundraising race, however you exercise.

25 February, London
Rare & Unclassified Bleeding Disorders Day
A unique event for people affected by very rare disorders.

4 March, Oxford
Talking Red Live
Our annual get-together focusing on women and girls with bleeding disorders.

25 March, Nottingham
Haemophilia Live
A day dedicated to key issues affecting people living with haemophilia.

17 April
World Haemophilia Day
Uniting the global community. Also the finish of our Race Around the World fundraiser.

21 - 23 April, Bolton
Newly Diagnosed Weekend
Essential support for young families. Subject to availability, register online.

23 April, London
London Marathon
Very good luck to all our awe-inspiring runners!

16-18 June, Derbyshire
Haemfest 2023
Camping, fun activities, workshops and good conversation.

26 - 30 July, Derby
Youth Camp
Adventures and confidence building for children and young adults with a bleeding disorder (and/or siblings). Subject to availability.

The Haemophilia Society

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