CORPORATE MEMBER ACKNOWLEDGEMENTS

HAEMOPHILIA SCOTLAND were delighted to receive confirmation from their previous two Platinum sponsors, SOBi and Novo Nordisk, of their wish to continue supporting the charity through this programme in 2024. With the addition of LFB Biopharmaceuticals last year, we now have the following companies helping to support our work towards improving the health and wellbeing of people in Scotland living with or affected by a bleeding disorder

Roche Chugai provide funding and support to Haemophilia Scotland as a Gold Corporate Member. Roche Chugai have had no influence on the content presented, unless where stated.

LFB Biopharmaceuticals has sponsored Haemophilia Scotland, through support via the Gold Membership package. LFB Biopharmaceuticals have had no influence on the content presented, unless where stated.

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the wire

HAEMOPHILIA SCOTLAND

ISSUE 12

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Scotland's Bleeding Disorders Charity
Registered Scottish charity: SC044298

World Federation of Haemophilia (WFH) Congress in Madrid

Haemophilia Scotland Receives Grants to Attend 2024 WFH Congress in Madrid:

Follow Us for Live Updates!

We are excited to share the fantastic news that we will be sending a delegation to the *World Federation of Haemophilia (WFH) Congress in Madrid on April 21-24.* This is thanks to grants received from ***SOBI*** and ***Pfizer***.

The WFH Congress, organised by the **World Federation of Hemophilia (WFH)**, stands as a premier event that gathers professionals, leaders and experts from various industries to discuss the latest developments, trends, challenges, and opportunities related to haemophilia and other bleeding disorders. The WFH is a global organisation dedicated to improving the lives of individuals with haemophilia and other bleeding disorders.

In ensuring our Scottish bleeding disorders community is represented at this international event, we are proud to be sending a delegation of four representatives to be ambassadors for us. They are, *Alan Martin, Alex Whitteker, Joanne Kirkham (Trustee) and Kimberley Stewart-Beasley (Member)*. These ambassadors will go to seminars, attend workshops, and engage in networking sessions to bring back valuable insights to share with our community.

We express gratitude to SOBI and Pfizer for their provision of a grant to enable us to attend the Congress.

As we embark on this exciting journey to Madrid, we invite you to join us virtually by following Haemophilia Scotland on our social media platforms. We will be actively sharing live updates, behind-the-scenes glimpses, and key takeaways from the WFH Congress.

- Follow Haemophilia Scotland on **Facebook**: *www.facebook.com/HaemophiliaScotland*
- Follow Haemophilia Scotland on **Twitter/X**: *www.twitter.com/HaemophiliaScot*
- Follow Haemophilia Scotland on **Instagram**: *@haemophiliascotland*

Onwards and Upwards

In this issue of *THE WIRE*, we hear from several of our younger members who tell us a little about themselves and their experiences of living with a bleeding disorder

ABOVE: Kyle enjoys the great outdoors, particularly forest activities.

RIGHT: 12-year old Zeb is very competitive and delighted on being awarded his purple belt in karate.

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Why not contribute your story to the next edition?

UKHCDO Peer Review of Haemophilia Comprehensive Care Centres

by John Dearden

The United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO for short) is an association of consultants and other doctors who are engaged in the care of patients with bleeding disorders.

The organisation's aims are to improve the treatment of those with Haemophilia and other bleeding disorders; to raise awareness of these conditions; engage in the education of medical, nursing and allied health professionals; and to conduct audit and research. They bring together expertise from the four countries of the UK and maintain a central database on treatment, which is used for research into bleeding disorders.

Every five years the UKHCDO undertake a Peer Review of Haemophilia Comprehensive Care Centres to examine whether Centres are meeting national standards for the care of those with inherited and acquired bleeding disorders. The Reviews look at how services and clinical outcomes can be improved for patients and carers. The three Comprehensive Care centres in Scotland (Royal Infirmary Edinburgh, Glasgow Royal Infirmary Adults and Glasgow Hospital for Children) will each be required to participate in the reviews.

The reviews are undertaken by clinicians from across the UK reviewing systems and practice in other parts of the country. Whilst they concentrate on the work of the Haemophilia Centre, the reviews will also look at how the centres interact with other services such as A&E, surgery, dentistry, physiotherapy, psychology and genetics.

Haemophilia Scotland Co-Chair, John Dearden

The views of patients are an essential element of the peer review process. Significantly at each review there will be a patient representative who will contribute to the process as a full member of the review team.

Each Centre is required to show that they survey patients on their experience of their care and the facilities at the Centre. As reviews start to happen from March 2024, you may be asked by your Centre to complete a questionnaire or survey. If asked, please do respond. The questionnaire will not take long to complete and will be really helpful to the review team. Should you wish to look at the standards on which the reviews are based, details are available via our website or by following the link:

https://rb.gy/lzpif3

The Peer Review process is important to Haemophilia Scotland as we can use the results to discuss with Centres areas for improvement in the delivery of services. It also allows the Centres to share areas of good practice with colleagues across the UK and to reflect on how they may improve services at their Centre.

Once all the reviews are completed a UK-wide report will be published summarising the findings. That should be published late in 2024. We will let you know the outcome in a future edition of The Wire.

Reflections and what will the new year bring?

Reflections and what will the new year bring?

HAEMOPHILIA
SCOTLAND

Alan Martin
Director, Haemophilia Scotland

WELCOME TO THE LATEST EDITION OF **THE WIRE** NEWSLETTER. January, despite its challenging weather and post-Christmas blues for everyone, also serves as an ideal time to reflect on the organisation's accomplishments from the previous year and prepare ourselves for the upcoming one. If I thought last year was busy, however, 2024 is already showing signs of surpassing it by a significant margin.

Last year, we successfully launched several new events and projects that I take great pride in. In August, we received the finished copy of the young members' comic book, **'Living with a Bleeding Disorder'**, which is now available online and physical copies also distributed to all the Haemophilia Centres. This serves as a helpful educational tool for any children living with a bleeding disorder and will be equally beneficial for friends and family seeking a better understanding of their daily experiences. We cannot wait to get started later this year on the second comic book in the three-year project.

During that same month, we published the final report from our **Needs Assessment** survey and unveiled the organisation's **Strategic Outline** for the next three-five years. These were both presented at our **AGM and Clan Gathering Members Day**, offering a clear vision of our organisational status, outlining the main priorities identified by our members, and how we are intending to work on these goals over the coming years.

These two publications have been very influential with our new projects for 2024 and address some of the key issues raised by the outcomes from the **Needs Assessment**: namely, access to specialist services such as physiotherapy; information and support on financial benefits available to people with bleeding disorders; and to ensure that our events are available to as many members as possible.

This year kicked off with the successful launch of our **Join the Movement** virtual physiotherapy programme, which has proven to be very popular and led to the addition of a third block of classes for members to sign up to. It has been great to see the range of members that have signed up to the class and hope that everyone involved will benefit from this specialist physiotherapy programme from the comfort of their own homes.

We also began the recruitment of the new **Financial Wellbeing Officer** position which we are confident will swiftly become an essential resource for members seeking guidance on benefits, welfare and financial wellbeing matters. With the aim of filling this position by Easter, we are eager to make this valuable service accessible to all our members as soon as possible.

In March we hosted **Female Factors: A Conference for Women's Health** in Stirling, which had been in development since last year. This provided an opportunity for women with a bleeding disorder, a carrier or a family member of someone with a bleeding disorder, to come together, share their experiences and discuss a range of issues with each other. We were delighted that Dr Julia Anderson, Consultant Haematologist at the Edinburgh Centre, was guest speaker at the event and shared some of her valuable insights.

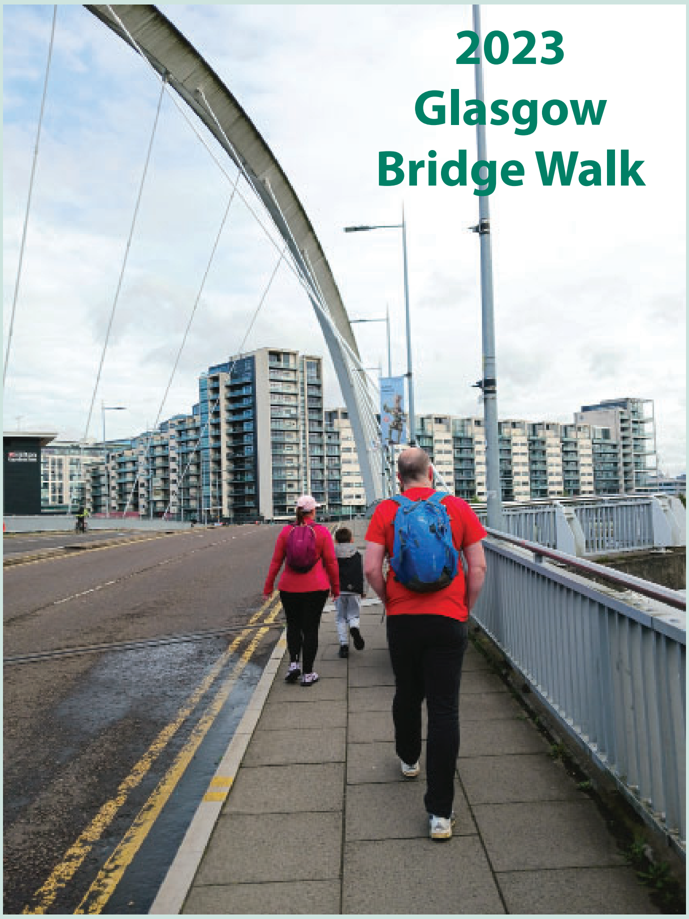
The much-anticipated final report of the **UK Infected Blood Inquiry** is now scheduled for publication in **May 2024**. We are hopeful that the recommendations outlined in the report, coupled with ongoing legislative progress made these past two months, will ultimately pave the way for justice for all our members directly or indirectly impacted by this horrific scandal.

Later this year we will also be hosting a series of patient information mornings at each of the Haemophilia Centres with our **Learn and Connect** project. The purpose of these events is to bring our local communities together and give our members from as many regions as possible the chance to attend one of our events, reconnect with old friends or meet new acquaintances. Details for each event will be announced throughout the year and will be a great opportunity to meet with Haemophilia Scotland staff and our guest medical professionals present on the day.

This is just a glimpse of what 2024 has in store for us and we really hope to match or even surpass the success we had last year.

I hope to see you all at our future events in the coming months.

2023 Glasgow Bridge Walk



Clearly not 'A Bridge Too Far' for enthusiastic walkers during the **Glasgow Bridge Walk**, who raised an impressive £590.67

TOP RIGHT: Zig-zagging across the River Clyde, among other contributors to the success of the event, were Alex Whitteker, Helen Cook and Alan Martin

To raise awareness and funds for our Scottish bleeding disorders community, a small group of us participated in the **2023 Glasgow Bridge Walk**. This was an event organised in association with **The Haemophilia Society**.

We started and finished at the Riverside Museum, with the 10km walk having us zig-zagging across the River Clyde. A huge 'thank you' to everyone who participated in the fundraising event, whether it was by joining in on the walk or by making a donation, which enabled us to successfully raise funds and awareness on behalf of our community. In total, **we raised £590.67, inclusive of Gift Aid**, with half of the proceeds going to The Haemophilia Society.

Haemophilia Scotland attends SIBDN Education Day

On Friday 3rd November 2023, Haemophilia Scotland staff and Co-chairs attended the annual Scottish Inherited Bleeding Disorders Network (SIBDN) Education Day.

The event was held at the COSLA Building in Edinburgh and was attended by healthcare professionals from all across Scotland, offering an excellent opportunity for us to connect with representatives from each of the six haemophilia centres in Scotland.

Haemophilia Scotland Director, Alan Martin, gave an update on our organisational activities and officially launched 'Join the Movement', our virtual physiotherapy project.

Thank you to SIBDN for organising the informative and educational day.

It's hard to be a patient, infected blood, patient!

The news that the publication of the ***Infected Blood Inquiry (IBI) Report*** has been further delayed until May 20th will have come as further frustration to the many affected who want to move beyond the present apparent intransigence of the UK Government to act on the IBI recommendations published last April.

That frustration will, of course, be compounded by the Government's pronouncements to pay out on compensation for the Post Office victims following the 'Mr Bates vs The Post Office' drama on ITV. They have said compensation payments for PO victims do not have to wait for the Horizon Inquiry final report.

The damage already done to infected blood survivors has been aggravated. Not only that, but more and more of those infected have not survived to benefit from compensation payments or see justice while awaiting positive news from Government.

Having attended the funeral of Simon Hamilton between Xmas and New Year, the raw cruelty of the Government position was particularly stark.

Simon was the chair of **Haemophilia Northern Ireland** who I worked closely with in seeking justice for infected blood victims. It was by no means the first funeral of those infected that I have attended over a 20 plus year period.

"The damage already done to infected blood survivors has been aggravated. Not only that, but more and more of those infected have not survived to benefit from compensation payments or see justice......"

I mention all this not to further fuel the anger many are feeling, but to acknowledge my own sense of frustration at where we are.

However, there are some positives to focus on.

Haemophilia Scotland Co-Chair, Bill Wright, has been a core participant and closely followed the work of the Infected Blood Inquiry since it began its deliberations on 2 July 2018

Infected Blood Inquiry

"This is an independent public statutory Inquiry established to examine the circumstances in which men, women and children treated by national Health Services in the United Kingdom were given infected blood and infected blood products, in particular since 1970."

https://www.infectedbloodinquiry.org.uk/

Firstly, the Horizon scandal at The Post Office is prompting some media commentators to draw parallels with the Infected Blood Scandal. While 'Mr Bates vs the Post Office' might have drawn attention to the scandalous treatment of postmasters, that situation is potentially offering a platform for stories on 'our scandal' to get greater exposure and be believed.

Secondly, the success in Parliament of an amendment to the Victims and Prisoners Bill compels the Government to act on compensation for infected blood in a given time period.

We continue to press Government to meet and talk to them reasonably about what needs to be done. We will keep trying and Haemophilia Northern Ireland will be with us in doing so.

It is frankly in no-one's interests to extend this Inquiry one minute longer than is needed to ensure it reaches its proper conclusions and makes sound recommendations. The Inquiry team want to move on, survivors want the IBI Report as soon as possible, and health practitioners and services need to get those recommendations to act on them.

"The Report will set out and explain the many failings at systemic, collective and individual levels over more than six decades....."

So, I take heart now that we have an actual date for the Report and to the dedication Sir Brian and his team are applying to their momentous task. The Inquiry, when announcing the date, stated:

"The Report will set out and explain the many failings at systemic, collective and individual levels over more than six decades. Finalising a Report of this magnitude, in terms of the sheer scale and seriousness of the criticisms, is complex".

That is a very significant signal of what the Inquiry is thinking.

Please stay well.

Bill.

Out and About with our Members

'Being a young haemophiliac' AND 'Transitioning from child to adult services'

pages 6 - 12

29-year-old Iain Gordon-Smith offers a personal perspective on his experience of progressing from children's to adult clinical care

Growing up is weird. From as far back as we can remember, everybody else around us was always way bigger than us, always wiser and always knew so much more than we could ever imagine. For most of us, there always seemed to be somebody around to watch our backs, keep us right and guide us through whatever endeavour we found ourselves in. But then, all of a sudden, life is up to us. From enjoying all of the seemingly endless support and guidance over the years, eventually the world changes its mind and decides that those 'big people' decisions are now ours to make. From being small, we become large, and from being the youngest in the room, suddenly there's someone new to take our place. This is the transition from childhood to adulthood.

Now, obviously, I'm simplifying the process a little bit; life is more gradual and we don't usually become so responsible as quickly. Eventually, the responsibility of our lives does become fully ours though. In the case of haemophilia, or living with any bleeding disorder, this means that from having a watchful parent to make decisions regarding our care we then become the decider in how to deal with our condition and injuries as and when they arise. Injuries which, as an adult, much like as a child, do sometimes get in the way of our work and fun.

Soldier Field stadium in Chicago, Illinois: a venue for major musical and sporting events, including being the home of NFL giants, the Chicago Bears

Being well equipped with all the experiences from childhood and 'teendome', however, our instincts, by this point in our lives, should be well informed as to how we must deal with our 'condition' related issues exactly as and when they come up. For me, being a moderate haemophiliac and not on prophylaxis, luckily, I don't have to take time out of two or three days every week for regular injections of factor. I have, however, had my fair share of occasions which required that I make informed, adult decisions regarding my haemophilia care. Occasions where the world-famous mantra of, "it'll be fine", really wasn't going to cut it.

So, here's a good story:

When I was 19, my then girlfriend and I were lucky enough to be invited to go to work backstage at big rock and pop concerts in Chicago, USA. Our job was to be part of the catering crew. So, we were helping in the kitchens, loading and unloading trucks with ingredients, portable grills and cookers, setting up dining and dressing rooms and for when there was nothing else, we had no shortage of dishes to do. One night, when we were finishing up at a Beyoncé and Jay Z concert in Soldier Field (where we were told Barack Obama had held up the performance in order to chat to the said popstars), we were re-loading the trucks full of all that heavy equipment when I ended up having a bleed, which I had to make one of those 'informed adult decisions' about.

The equipment we were loading included tall metal trolleys loaded with lots of additional kitchen items – pots, pans, cooking trays, utensils, etc. Shortly put, this thing was tall and heavy. As myself and another were hauling the trolley along, we arrived at a hill before making it down to the truck below. I was on the bottom side of the trolley, so was carrying the weight while my fellow crew member was holding on at the top, helping to guide and move us at a slower pace. As we went down the hill we began to gather speed and lose control of the trolley to the point that it rolled right over my big toe. Now for anyone this is going to hurt, a lot. So, I naturally went to take some time out to gather myself - something which everybody else around me could reasonably understand. For me though, being very aware of my pain thresholds relating to my haemophilia, I very quickly knew that this was an injury which was definitely going to need some treatment!

So, I ran back to the kitchen, got myself some ice, which I wrapped in a dish towel, sat down, and held to my big toe.

With this happening at around 11pm or midnight, however, and with everyone having already been on their feet from about six in the morning, we were all tired and in need of a good rest. Not wanting to let the team down at the final stage of the day, a usual decision from most other people would be to 'take 5' and then continue pitching in to get the job done – this is part of the job after all, accidents happen and how bad can my big toe really be? I could have easily shrugged it off and said, "I'll be fine", and continued working – as I had done on many occasions in my life while growing up. I also knew, however, that, "starting tomorrow", we were all going to be at the Lollapalooza festival, working the same 10 to 14 plus hour days on our feet for the next week and a half or so.

So, I could either keep working that night, be paid to work and not risk looking like a slacker, while also running the risk of not working over the next few days due to the injury (and not being paid for those days). Or, I could sit the last hour out, treat myself with the ice (and factor when I got home) and be right as rain by the morning to continue working all through the week ahead – and make all the money that I expected to make in the process. So, I took the latter option and explained my situation to the rest of the group (with help from my girlfriend) and sat out for the final hour while the rest of the team finished up on the job. We then got home where I further treated myself with a healthy dose of factor, given to me for my trip from my haemophilia centre in Glasgow (who knew where I was going, for how long and therefore how much factor I should take with me).

True to my instinct and experience, the next day I was back on my feet, working for another 10 to 14+ hours, and then able to do the same every day for the following week and more. I trusted myself with my treatment and was back on my feet in no time at all. I made all the money I was set to make, didn't have to go to hospital and had another three weeks of work and fun in a really cool city with my girlfriend.

So as your care transitions from child to adult services, my advice for you is to trust your instincts. Sitting out for an hour is better than sitting out for a week, and when having an injury, we must not be afraid to let everybody know exactly what it is that we need and nothing less, especially in a working/pressured environment, remembering all those times where you didn't treat a bleed straight away and compare them with the times you did.

As we grow and our healthcare needs move from child to adult services, we must appreciate that our health, much like all the other elements of our lives, really does become our own responsibly. As we leave home and go off on our own adventures, taking ownership and responsibility for our condition is what sees us do the best with our lives. As haemophiliacs, or people with any bleeding disorder, living in Scotland and the UK (I live in London mostly) we are among the luckiest of people in history to ever live with these conditions. The level of care that we have is nothing short of a miracle and has granted us a quality of life which was historically unheard of and to this day is still relatively unknown to much of the world - and it's here for your use and benefit.

So, go out into the world feeling empowered by your experiences so far and trust those experiences to guide you through your personal haemophilia and bleeding-related needs. You already know when you need to take your prophylaxis, when a bash needs an ice pack and more, and especially when, "it'll be fine" will really not be fine. Be aware of how activities can and will affect you, but never be afraid to undertake them – that's what the ice and factor are for (particularly the ice!). And as a final note, do turn up to your haematology check-ups at your centre and keep in touch. You never know when you're going to really need their help. So, the more they know you, and know about you, the better help and guidance you will continue to receive right through your new, weird, 'grown up' lives.

Much love and best of luck.

UPDATE ON 2024 EVENTS

We are pulling together our **Events Programme** for the year. Aside from the **Virtual Physiotherapy Project**, **Women's Conference** and **Teens Comic Book Workshop**, we are also planning: an **event for people aged 50+ affected by a bleeding disorder**; a **Family Day**; the **Haemophilia Scotland AGM** and **Coffee Mornings** in **Inverness, Aberdeen, Dundee and Edinburgh**.

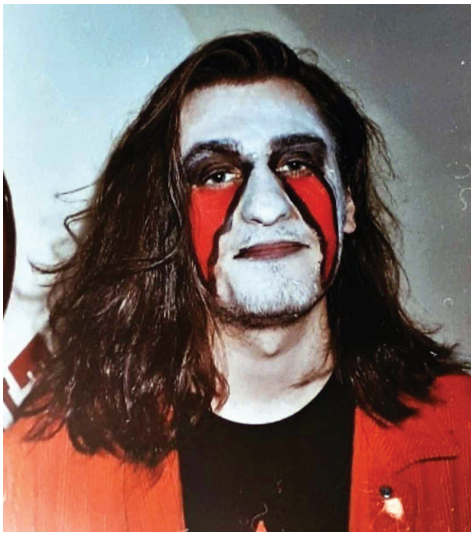
For up-to-date information on our events programme, visit our website:

https://haemophilia.scot/support/events/

and follow us on social media:

- Follow Haemophilia Scotland on **Facebook**:
  www.facebook.com/HaemophiliaScotland
- Follow Haemophilia Scotland on **Twitter**:
  www.twitter.com/HaemophiliaScot
- Follow Haemophilia Scotland on **Instagram**:
  @haemophiliascotland

Out and About with our Members



Daniel McGuigan

I've been asked to write about my experience of living with a bleeding disorder. So, here is my story.

My name is Daniel and I'm aged 28 and have Severe Haemophilia A. That's right, the bad one. Just kidding, it's not so bad. Maybe sometimes but, for the most part, it's fine. For those of you who don't know, basically my blood doesn't clot, and that's pretty much it.

Growing up with haemophilia was never boring. Not only did I inherit the bleeding gene, but I also inherited the clumsy gene, which go hand-in-hand together, like Ant and Dec, but if they made you bleed instead of smile. It got rough from time to time, but it's absolutely manageable. If you can laugh and enjoy the bits in-between having bleeds, then you've conquered haemophilia.

If you're unfortunate enough to have haemophilia you'll know it can be a bit scary from time to time, particularly when transitioning from a children's hospital to a big boy hospital. When I made the big leap, I remember being very nervous, but mostly because being the only person in my family to ever have a bleeding disorder, I'd never actually seen a haemophiliac over the age of ten – Ever! I didn't know they existed. But they do, and they're sound. However, it's normal to feel scared, as you're not just changing hospitals, you're also letting go of a part of your childhood; you're growing up. In fact, it may be the worst thing to happen to us since, well, the whole bleeding thing. Not only that, but the safety you feel in the company of the nurses and doctors may feel irreplaceable, but I guarantee that your new nurses and doctors will make you feel right at home. You're in great hands and you've got nothing to worry about.

Unfortunately, I've been through it all. So, if you're worried about anything or you need any advice, you can always send me a message: just remember, you are not your condition, don't let it rule you. And it's okay to be scared. It's a scary situation, but everything will be fine, trust me. It could be worse, you could have a bleeding disorder… wait… okay, so maybe it couldn't be worse. At least you don't have haemophilia in the year 1672, imagine that? No YouTube or Fortnite either. Nightmare. Then again, they didn't have Simon Cowell or Love Island then either, so it wouldn't have been all bad.

Anyway, I'm going to go now as my girlfriend has just reminded me that I've forgotten to do my jag. That's right, I have a girlfriend. See, anything is possible!

Rory and Cal

Both boys have Severe Haemophilia A and always take part in activities on holidays, like archery, fishing, segways, axe throwing, laser tag, etc. They both enjoy swimming and Cal loves playing football at school.

Both boys did TKD Tigers and now do Junior Korean Kickboxing. Cal has also just started on his Taekwondo journey, and after 7 years of hard work, Rory recently passed his Junior Blackbelt Taekwondo grading. They don't spar competitively, but Rory is talented at patterns and has had a lot of medal success at competitions.

When he was aged five, meeting Jack Bridge, a Paralympic swimmer who has Haemophilia, inspired Rory and he wanted to win a medal just like Jack.

The two boys also exercise their fingers very well playing regularly on their Xboxes.

Although Haemophilia can be rubbish sometimes, with jags and sore bits, etc, they definitely don't let it stop them having fun and staying fit.

ABOVE LEFT: The boys with their dad, Dan
ABOVE: Cal and Rory enjoy martial arts

Zeb rewarded with Purple Belt

Zeb is very keen on sports, but is equally keen to stress the importance of wearing suitable protective clothing when required. On one occasion, he went over his bike's handlebars and landed heavily on his back, which left an impression on his skin of the body armour he was wearing. Clearly, the protective gear helped cushion him from the impact of his fall.

Zeb says, "It's important to wear helmet, gloves, knee pads, elbow pads and body armour."

~

I'm Zeb and I am 12 years old and in my last year of primary school. I enjoy mountain biking, skiing, having fun, running around, going on holiday, water polo, karate, and scouts, BUT school sucks (some of the time!). Oh, and by the way, I am a Severe Haemophilic.

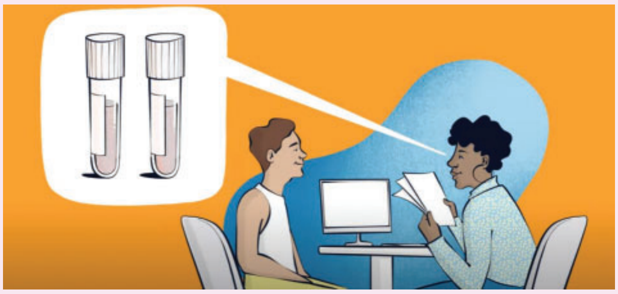
The highlights of my year include achieving my purple belt in karate (brown belt next); getting my bronze star in French ski school, meaning that I have been assessed to have the skills and ability to ski black runs (the hardest in the resort); and mountain biking with my family in the summer holidays, where I use the ski lifts to take me up the mountain so I can enjoy the down.

Family summer holiday in Les Arc, French Alps. My bike and I are getting a ski lift to the top of the mountain.

Very happy having just impressed a panel of judges to gain my purple belt in karate.

At the top of the mountain and looking a little apprehensive before taking on the longest black run in Europe. I always ski with my medication in the hood of my jacket, just in case the worst happens (you can just see the bag poking out from round the back of my helmet).

The **Local Families with Bleeding Disorders (LFWBD)** charity launched a short, animated film this year on self-advocacy for people living with a bleeding disorder.



"As people living with bleeding disorders, we are the experts in managing our own lives. That means at times we need to speak up for ourselves or, in other words, self-advocate.

Self-advocacy means telling people what's important to you; both about your health and your wider life understanding of your condition, and being aware of your role in having a say in decisions about your care…"

Watch the short, animated film online at:

https://youtu.be/Z0G8UL7s5IU

JOSHUA'S STORY

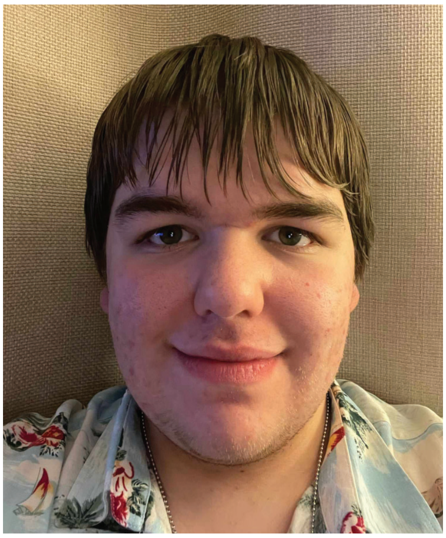
My name is Joshua Bramman. I am 16 years old, and I am a Severe Type A Haemophiliac. I have a family history of Haemophila, which was diagnosed when my uncle was about one year old. There was no family history until then. Subsequent family testing showed that my Mam, aunt and Grandma were all carriers. My cousin is also a Haemophiliac and my sister is a probable carrier based on Factor 8 levels. I was diagnosed the day after I was born.

I guess growing up with so many affected people has given me an insight into how things day-to-day can be challenging, but can also be managed accordingly. Plans may need to be changed at the last minute; sudden arrangements may need to be made to accommodate mobility challenges. Sometimes events just don't happen at all because I am unable to take part. That really frustrates me and annoys me that I have Haemophilia because it can at times have a major disruptive effect on my life. When I have a bleed and can go to school, either using my wheelchair or crutches, particular perks include being able to use the lift like a boss, get my lunch early and both go into class later and leave early to miss the rush and congestion. I usually have a friend with me to help with my bag and for company, and I have no difficulty in finding a volunteer. I can't think why?

There are times though that I am unable to go to school at all due to pain and prolonged recovery. I don't enjoy it when I have bleeds like this as it means it's not just going to school that is affected, its everything: going to youth forum, going to guitar lessons, even just hanging out with my friends. It can be quite isolating at times, and I feel it is really important to be positive and try to not get down and upset. Haemophilia is not only a medical condition; it does affect how you feel too. When it is like this, my friends and I keep in touch by phone or on the PlayStation and it's nice to know they still want to include me and think about me.

Occasionally, I must miss out on PE due to bleeds (no great loss since I am built like an athlete anyway, as you can tell), but I am always included in other ways so that I still feel part of the class and valued. When I do have a bleed, classes are changed and adapted to help me. If I can't write, I get slides or a printout, and if I can't get to a certain area then things are brought to me. I have been lucky that I have the same friends at Academy that I have had since Primary School, so they have always known about my Haemophilia and how it can affect me. I guess in a way they have been brought up with it as I have and can tell when I am not feeling well or have hurt myself. At times it has felt like I have had several mams and dads looking out for me, especially when I have decided not to say anything about a bleed that I have caused being silly, but find out that Mam has already been made aware by my minders. They have always been understanding, helpful and supportive with everything I have done in my life, and I know that I can always count on them, both now and in the future.

I can tell now when I am having a bleed as I know how it affects me and how it can feel. There are a few sensations depending on how early the bleed is. Usually, it begins with a dull throb, like a buzzing feeling, like an electric current. Gradually, the pressure builds up in the area, making it feel tight, hot and swollen, like you are filling up a glass of water to the top. The pain increases and intensifies to the point it is agony but I have usually intervened before this happens. If the bleed is internal or in a joint, sometimes there are no outward signs to indicate there is a problem, but I can feel when things are not right. Sometimes though, I think that there are times I don't need to say about having done something. But really, I should just say something when it happens. I know I do this because at the time I don't want my Haemophilia to get in the way of what I am doing. It can be an inconvenience. Sometimes, I would say I wish I didn't have it as it does disrupt events. Only last week I had to come away from my Bronze Duke of Edinburgh expedition as I developed an ankle bleed overnight. I continued walking on my sore foot for the following morning until it became unbearable to weight-bear. I didn't want to let the rest of my team down and didn't want to miss out on earning my award either, but I had to admit defeat as the pain was too much for me to take anymore, and Mam had to come and get me and take me to Aberdeen to be reviewed. I was off school for a week and was found to be positive for Covid too. You can only imagine and sympathise with me as to how Mam's mood was in the car when I said to her, I had been having a bleed for at least 12 hours and didn't say anything earlier.



I know Mam and Dad mean well and will always look out for me. I know they only want the best for me and that I need to respect my condition and manage it to stop having long-term issues. The ex-nurse always kicks in at consults and reviews. I think Mam finds it hard that I am a young adult now and I need to find out things for myself, usually the hard way. She says mams know everything. Does she though? She is getting better at stepping back and knows that I can make decisions about my treatments and management now, even though she still can't help herself asking questions and wanting to know more, where I would just agree, maybe too easily. Sometimes it helps to have another person listening, supporting and thinking about stuff I wouldn't have myself. This will help me going forward when I transition to adult services soon.

This all helped 18 months ago, when I had the opportunity to change over onto fortnightly sub-cutaneous injections for my Haemophilia instead of the alternate day treatments that I had been on for over 14 years. It was a big step for us all. I couldn't wait to get started. I could immediately see all the benefits: less hassle, more freedom, the ability to manage my treatment myself as I had particularly poor venous access. I had play therapy and counselling for needle phobia in the past. Five previous central-line ports resulted in me developing septic shock and an airlift to Edinburgh when I was aged six, which meant I was poorly and rehabilitating for six months and had to learn to do a lot of things all over again.

There have been some teething issues; to be expected with anything new. I still need oral clotting agents to manage a traumatic bleed initially and will need my old factor medication intravenously as a top-up for surgery and problematic bleeds. My new medication has needed to be adjusted a few times to find the right dose for me, but so far things are working relatively well. I have had a few small breakthrough bleeds as the new treatment does not work the same way as my old regime. But I am happier on this type of injection, as opposed to finding a vein, which was frequently very difficult for me and my parents. I continue to be reviewed regularly at hospital and pop up unannounced too. But the team at Aberdeen always have my back and look after me.

> *"Effective management has given me more freedom and opportunities to forget about Haemophilia and, indeed, having Haemophilia has given me the chance to do things I wouldn't have been able to access otherwise."*

Effective management has given me more freedom and opportunities to forget about Haemophilia and, indeed, having Haemophilia has given me the chance to do things I wouldn't have been able to access otherwise. I have been to several residential camps run by charities that allow children with health conditions to take part and be included in something bigger. These are held in England, Scotland and Ireland throughout the year. They have key workers, helpers, mentors, medical and nursing staff, physios... everything. I had the chance to meet other people with Haemophilia from all over Europe and someone who has Haemophilia B. Maybe one day I will be able to volunteer and help at these camps. I have been able to fundraise and, in turn, raise awareness of Haemophilia and what it is. It allows people to ask questions; no question is silly. I mean, how can anyone learn if they don't ask? Things like, "Oh, is that where you just keep bleeding and bleeding?" or, "Are you okay to use scissors?" have been asked over the years. But, if people don't know and want to learn more, then I am open and willing to help increase their knowledge.

I no longer see Haemophilia as a hindrance, an inconvenience, at times a total pain. I see it as having opportunity, inclusion and understanding. That comes with maturity, grounding and developing as a young adult. Being able to accept Haemophilia, and all it comes with, has played a big part in being more open to looking ahead, and thinking about what the future holds for me.

Soon, I will be starting driving lessons having been given a grant through Motability to do so. I will sit my Prelims in November and hopefully get an indication if a Modern Studies Teacher is a possibility for my career. I enjoy outdoor pursuits, such as clay pigeon shooting and fishing. I will continue my guitar lessons and my youth work as part of the Forum. I hope to get my motorbike licence and get a tattoo too.

I would like others in a similar situation as myself to see that Haemophilia shouldn't hold you back from fulfilling what you want to do with your life. It is your life after all, no one else's and you should live it as fully as possible.

So, on that note: My name is Joshua. I am aged 16 and I have Severe Haemophilia A.

I have Haemophilia, but it doesn't have me.

NEWS FROM SCOTLAND'S HAEMOPHILIA CENTRES

Retiral of Dr Alvi from Glasgow Adults' Haemophilia Centre

The **Glasgow Adult Haemophilia Centre** is sad to announce the retiral of its **Associate Specialist, Dr Alvi**. After nearly 20 years of service at the Centre, he has decided it's time to hang up his stethoscope for a well-earned rest and time with his family.

A retirement party was held for him at the haemophilia unit on Friday 2nd February and Alan Martin and Alex Whitteker attended to give thanks and congratulations on behalf of our bleeding disorders community.

New Data Manager appointed at Glasgow Children's Haemophilia Unit

The team at the **Glasgow Children's Haemophilia Unit** are happy to welcome to the team, **Vicki Moffat**, who is their new Data Manager.

Haemophilia Scotland congratulates Vicki on her appointment and looks forward to working with her.

Kyle and the great outdoors

KYLE ENJOYS BEING OUTDOORS. Since being a toddler, he has been able to attend forest activities, initially with nursery then throughout primary and during secondary school.

You may recall that Kyle did a sponsored walk during Covid for Haemophilia Scotland (@HaemScot) and achieved his Emerald North Lanarkshire Council Achievement Award? Well, he's working on the next one and using the 'Wildlife Passport' to learn for it with the support of Under The Tree Outdoor Learning during forest sessions each week.

After a sometimes-tricky week at school, Friday afternoons in the forest are a great way to unwind and process the week. He benefits from the happy hormone, oxytocin, by using the swing. After forest we have an early tea and Kyle attends his third session of the week with his swimming club. Kyle will tell you he enjoys his swimming and it has become such a part of his routine that if he can't attend his day feels wrong. Swimming is sponsored by the Little Bleeders sports programme (@LittleBleeders), and we thank them and recognise that this makes a terrific difference to Kyle's physical and emotional health, his muscle strength, balance, coordination, breathing and core strength, which are developing well, and there are improvements in his gross motor skills and now fine motor skills. His quest for adventure includes looking forward to tree trekking and zip-lining on holiday.

This year he's hoping for a Haemophilia Scotland meet up as he misses them, and has fond memories of activity days.

Fundraising opportunities

Consider taking part in a fundraiser in 2024 to raise awareness and funds for our membership charity, Haemophilia Scotland.

Whether you're considering a daring challenge or a creative fundraising endeavour, your efforts will make a real difference in the lives of those affected by a bleeding disorder in Scotland.

Ready to take on the challenge? Let us know, and we'll provide you with all the support you need to make your fundraiser a wonderful success!

Remember, the possibilities are endless when it comes to fundraising creativity! Let your imagination run wild and, together, we can make a meaningful impact on the lives of those living with a bleeding disorder in Scotland.

Need some inspiration? Here are a few, fun, fundraising ideas that may get you started:

- **Cook-Off Competition:** Host a cooking competition where participants showcase their culinary skills, charging an entry fee for competitors and selling tickets for spectators to taste and vote on the best dishes.
- **Online Auction:** Gather donated items and host an online auction, inviting people to bid on their favourites, with all proceeds benefiting **Haemophilia Scotland**.
- **Themed Costume Party:** Organise a themed costume party or virtual costume contest, encouraging attendees to dress up according to a chosen theme and charging an entry fee.
- **Artistic Fundraiser:** Host an art exhibition or online art sale featuring works donated by local artists, with a portion of the proceeds going to support **Haemophilia Scotland**.
- **Trivia Night:** Host a virtual trivia night, charging an entry fee for teams to participate and offering prizes for the winners, with all proceeds supporting the cause.
- **Organised Running/Outdoor Event:** Take part in an organised event and set up a **JustGiving** fundraising page with proceeds going to Haemophilia Scotland

2023 Haemophilia Scotland Clan Gathering & AGM

Our appreciation to everyone who was able to join us at our Clan Gathering & AGM on Saturday 19th August 2023 at The Westerwood Hotel in Cumbernauld.

The day started off with a talk by the Edinburgh Centre Director, Dr Andrew Page, who delivered an informative presentation on treatments. It covered how the treatments work, currently available treatment, and the future in respect of treatments for haemophilia and other bleeding disorders.

Following Dr Page's talk, we heard stories from **Haemophilia Scotland** members, Louis and Kimberley, who shared their personal experiences of living with a bleeding disorder and the choices they made on improving the management of their, or their child's, bleeding disorder.

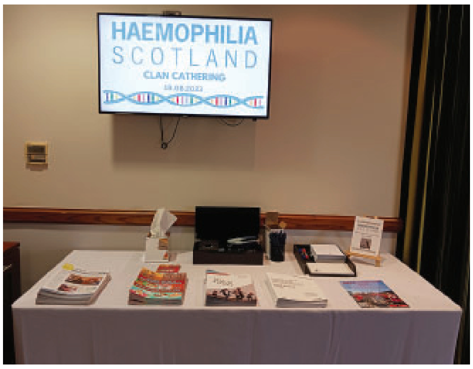
In the **AGM** segment of the day, the three longest serving trustees, Bill Wright, John Dearden and Gregor McInnes, were re-elected to the Board.

Haemophilia Scotland Director, Alan Martin, outlines the findings of the 2023 Needs Assessment Report

Following lunch, **Haemophilia Scotland Director, Alan Martin**, delivered a presentation on the findings of the 2023 **Needs Assessment**. If you haven't read the report ***(Exploring the needs of people living with bleeding disorders - June 2023)***, it is available at:

https://rb.gy/kfyhil

We broke off into group discussions later in the afternoon, which was an engaging session with a selection of themed table talks on treatments, access and support and engagement with **Haemophilia Scotland**. Thank you to all who attended for their participation and contribution to these group discussions. The feedback has been collated and will feed into our objectives to support, inform and advocate on behalf of our Scottish bleeding disorders community.



There was plenty of informative literature available at the AGM about the work of Haemophilia Scotland

On the day, we also launched a few new publications, including our latest edition of our magazine, **The Wire**, and a comic book, ***Living with a bleeding disorder***, produced by Magic Torch with input from children living with and affected by haemophilia or a related condition.

We are grateful to everyone who attended and for the opportunity to connect with one another again.

FEMALE ♀ ♀ FACTORS : A Conference for Women Affected by Bleeding Disorders

On Saturday 16th March, we hosted our Female Factors conference at the Stirling Highland Hotel and wish to record our thanks to all who attended.

The event helped reaffirm the importance of creating spaces where women are able to come together to learn, support one another and amplify their voices. By participating actively throughout the day, sharing their insights and engaging in meaningful conversations, those who attended helped foster a sense of community and belonging that will continue to resonate long after the conference.

Haemophilia Scotland would like to express our heartfelt appreciation to the keynote speaker, consultant haematologist Dr Julia Anderson, for generously sharing her expertise and insight with us. We are also grateful to Kimberley Stewart-Beasley, Jane Stewart and Kay Mutch for sharing their stories. The contributions of participants were instrumental in sparking meaningful dialogue, providing inspiration, and equipping attendees with valuable insights and tools for navigating life with a bleeding disorder.

This conference was funded by the ***Women's Fund for Scotland***.

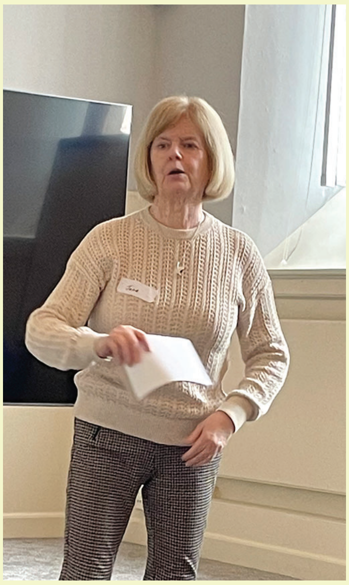
her hormonal therapies

ogestogen only preparations

nRH – gonadotrophin releasing hormone agonists: very effective, ometimes used to stop really active acute bleeding while a coil is fitted; main side effect is menopausal symptoms, so tends to be sued short-term

- Canues "add back" Hormone replacement therapy

Keynote speaker, Dr Julia Anderson



Some of the delegates and speakers who attended the conference in Stirling

Physical Activity and Transitioning Services

by Sean Lloyd

What does the transition to adult haemophilia services look like when it comes to physical activity and exercise?

Historically, people with bleeding disorders have been discouraged from participating in any kind of sporting activity due to the fear of bleeding. However, with advances in treatment, patients with severe haemophilia are on prophylaxis from a young age and those with milder forms of haemophilia are more informed when it comes to looking after themselves. Transitioning from children to adult health services can be daunting. However, when it comes to physical activity and exercise, you will hopefully be even more knowledgeable about your condition and how to manage it. It is also not too late to take up a new hobby or form of exercise. In fact, the transition is a great opportunity for you to speak to the consultant about the types of exercise you would be interested in trying.

The World Health organization recommend that adults should undertake at least **150 minutes of moderate-intensity aerobic physical activity** throughout the week. They also recommend that children and young people should accumulate at least **60 minutes of moderate to vigorous intensity physical activity** daily (WHO, 2020).

Now, I know what you're thinking: What exercise should I be doing? I'm told by my Centre that exercise is important, but I don't want to risk getting a bleed. Or, more commonly, parents worrying about having a bleed. This is coupled up now with being in the adult service and maybe feeling like you need to navigate through it all alone. It makes for a fine line in balancing the benefits of exercise with the risks. However, you're not. The Centres are there to support you in the best way possible. Hopefully, the information below will help you select the right exercise, which is usually the one you enjoy most.

The benefits of exercise are endless. Regular physical activity has been shown to improve bone health, cognitive function, academic performance, sleep, energy levels and self-esteem, to name a few. In addition, it has been shown to ***lower spontaneous joint bleeds*** [Tiktinsky el al (2002)].

Choosing the right activity can be tricky. Each person is unique, and the choice of the most suitable sports and exercise needs to be tailored. It is a decision that should be made collaboratively between ***you, your haematologist and your physiotherapist***. When selecting a sport/exercise, it is important to take into consideration your general health, past bleeding history and your joint health.

THE FOUR MAIN TYPES OF EXERCISE ARE:

- ***Aerobic*** (a brisk walk, jogging, biking, etc)
- ***Strengthening*** (Lifting weights, using resistance machines or body weight exercises, etc)
- ***Flexibility*** (stretching, yoga, etc)
- ***Balance*** (tai chi, standing on a single leg, etc)

There is no one type of exercise better than the other, but a combination makes for a healthier life.

PHOTO: a picture of me trying to paddleboard in Chicago last year, which is a great example of a Balance-based exercise.

CORPORATE MEMBER ACKNOWLEDGEMENTS

HAEMOPHILIA SCOTLAND were delighted to receive confirmation from their previous two Platinum sponsors, SOBi and Novo Nordisk, of their wish to continue supporting the charity through this programme in 2024. With the addition of LFB Biopharmaceuticals last year, we now have the following companies helping to support our work towards improving the health and wellbeing of people in Scotland living with or affected by a bleeding disorder:

Roche Chugai *provide funding and support to Haemophilia Scotland as a Gold Corporate Member. Roche Chugai have had no influence on the content presented, unless where stated.*

LFB Biopharmaceuticals *has sponsored Haemophilia Scotland, through support via the Gold Membership package. LFB Biopharmaceuticals have had no influence on the content presented, unless where stated.*

SOBi *provide funding and support to Haemophilia Scotland as a Platinum Corporate Member. SOBi have had no influence on the content presented, unless where stated.*

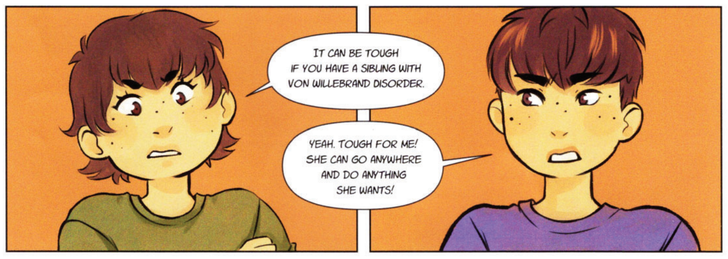
Novo Nordisk *provides funding and support to Haemophilia Scotland as a Platinum Corporate Member. Novo Nordisk have had no influence on the content presented, unless where stated.*

Comic Book Project: *Living with a bleeding disorder*

Last year, we began a three-year comic book project, in collaboration with the charity ***Magic Torch***, aimed at children and young adults aged 8-18 who are affected by a bleeding disorder.

We held the first workshop in March 2023 and will be hosting the second workshop, for teens aged 12-18, on **Saturday 7th September at the Quaker Hall on Victoria Terrace, Edinburgh**. The workshop will run until 3:30pm and we will go to "Can you Escape?" to do an Escape Room! Registration will be available via our website and social media soon.

Check out the comic book from last year's workshop via the QR code (below).



STORIES, THOUGHTS AND EXPERIENCES SHARED BY YOUNG PEOPLE LIVING WITH A BLEEDING DISORDER - FROM COMMON MISCONCEPTIONS TO WAYS YOU CAN HELPFULLY SUPPORT...

The proposed date for the ***Comic Book Workshop in September*** may be subject to change as arrangements for the ***Haemophilia Scotland AGM*** still need to be confirmed.

Please keep an eye on our website and social media for updates.

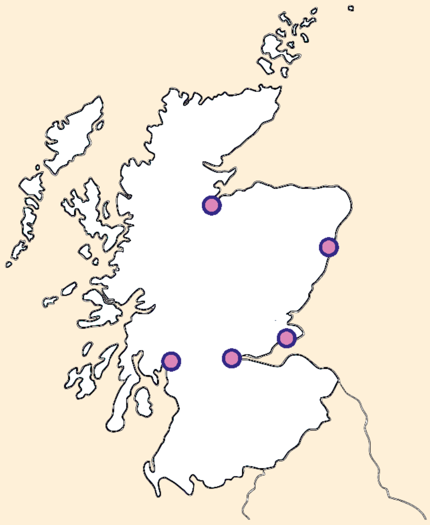
Learn & Connect Series

Haemophilia Scotland is coming to a town near you!

The ***Learn and Connect*** project was developed to help maximise opportunities for our members to meet and network with others across Scotland. To reach as many members as possible, we are hosting patient information mornings in each of the cities that has a Scottish Haemophilia Centre, namely **Aberdeen, Dundee, Edinburgh, Glasgow** and **Inverness**.

We hosted the first in our series in Glasgow in October 2023 and will make our way around Scotland over the course of the year. These are informal events that will run for 2-3 hours on a Saturday morning where there will be a couple of short talks and the chance to chat over coffee.

Haemophilia Scotland will provide a crèche and lunch. Keep an eye on our website and social media for dates. See you there!



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