the wire

HAEMOPHILIA SCOTLAND

ISSUE 15

Summer 2026

Scotland's Bleeding Disorders Charity

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New Advocacy Support Worker Role at Haemophilia Scotland

We are delighted to welcome Ruth Bidoni to the charity as our new Advocacy Support Worker, providing infected and affected individuals and their families with dedicated, compassionate and confidential support.

This new role reflects our commitment to ensuring that members don't have to navigate the complexities of the Infected Blood Compensation Scheme alone.

Ruth will be on hand to answer questions, explain the compensation process in clear and straightforward terms, and provide practical support when engaging with the Infected Blood Compensation Authority and other organisations. She will also help with other general advocacy issues affecting our members as needed.

We are excited to introduce this valuable new service and believe Ruth will make a real and lasting difference to the people we support.

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Mark's 2026 Marathon Double Raises Awareness and Support

Mark Morris with family and friends after completing the Edinburgh Marathon

MARK MORRIS completed his 2026 Marathon Challenge, running Manchester in 3:18 and Edinburgh in 3:37 to raise awareness and funds for Scotland's bleeding disorders community. It was a tough double of races, and his commitment, from training miles to race day grit, helped put a spotlight on the issues people with bleeding disorders face while raising valuable support for Haemophilia Scotland.

Mark completes the Manchester Marathon, raising over £5,000 between the two events

Across both events, Mark's determination translated into real impact: his fundraiser raised £5,200 plus Gift Aid; money that will go straight towards the services, information and advocacy that make a difference to people and families living with a bleeding disorder in Scotland. That figure is more than a number; it represents practical help, reassurance and resources for people who need them.

Of course, no challenge like this happens in isolation. We want to

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Why not contribute your story to the next edition?

Mark's 2026 Marathon Double

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say a huge thank you to everyone who played a part: the friends and family who ran training miles and offered moral support, the crowds who cheered along the route and lifted Mark's spirits, and everyone who donated or shared his fundraiser. Your encouragement, your messages, your donations and your presence all added up. They turned a personal challenge into a shared achievement that will have a lasting impact for people living with bleeding disorders across Scotland.

We are so proud of Mark. Not just for the times on the clock, but for the compassion and commitment behind them. We are also deeply grateful to the community that rallied around him. Achievements like this remind us that when people come together for a cause, they create momentum that carries far beyond the finish line.

Mark with some family support in the Scottish capital

Thank you, Mark, and thank you to everyone who supported him every step of the way.

HAEMOPHILIA SCOTLAND launched its ***Corporate Membership*** programme in 2022 to provide a more structured and transparent platform for companies to support our ongoing mission of improving the health and wellbeing of our members.

Through this initiative, our Corporate Members are able to demonstrate their commitment to the bleeding disorders community and receive recognition for their contribution to our work.

Our current members are:

NOVO NORDISK UK LTD *has provided financial support to Haemophilia Scotland via Platinum level Corporate Membership, but has had no involvement in our work or The Wire's content, apart from where otherwise stated.*

ROCHE PRODUCTS LTD AND CHUGAI PHARMA UK LTD *have provided financial support to Haemophilia Scotland via Gold level Corporate Membership, but has had no involvement in our work or The Wire's content, apart from where otherwise stated.*

SOBi *Provide funding and support to Haemophilia Scotland as a Platinum Corporate Member. SOBi has no control or influence over the Haemophilia Scotland website or the material it produces, unless where stated.*

Welcome to the Summer 2026 edition of *The Wire*

Alan Martin
Director,
Haemophilia Scotland

It seems like only yesterday that I was writing my last update on what the charity had been doing, and I can hardly believe that another year has already passed.

As always, the past year has been a busy one for ***Haemophilia Scotland***, but it has also been a year of building for the future and finding new ways to improve the services and support we offer our members.

We began 2026 by launching a new six-month awareness project focused on highlighting the day-to-day challenges faced by children and young adults living with, or affected by, bleeding disorders. The project brought young members together to share their experiences through a series of short videos and case studies, which we have been able to promote through social media and local newspapers. We also produced several longer videos showcasing the work of Haemophilia Scotland and the benefits of becoming a member, which we hope to share with haemophilia centres and online in the coming months. I would like to thank sincerely everyone who volunteered to take part and helped become champions for our community and the work we do.

Another highlight of the year was our continued commitment to raising awareness of women and girls with bleeding disorders, as well as those who may be living with an undiagnosed condition. At the beginning of June, we were delighted to host our second Women and Girls *'Female Factors'* Conference in Stirling. The event brought together women and girls with bleeding disorders, mothers of people with bleeding disorders, and invited guests for a day of discussion, learning and support. We were privileged to welcome Dr Laura Knox, Haematology Registrar from Glasgow, as our keynote speaker, alongside Kat Peddie from EndoSOS, a Scottish charity supporting women with endometriosis. The conference was a great success, and we will be taking forward the feedback and actions identified on the day as we continue to improve awareness, diagnosis and care for women and girls.

Looking ahead to the remainder of the year, we are delighted to have secured funding from *Pfizer*, *Roche* and *CSL Behring* to deliver our extremely popular ***Virtual Physiotherapy Programme*** once again this autumn. The programme will give members the opportunity to participate in physiotherapy classes led by Sean Lloyd, a physiotherapist who also has haemophilia. As in previous years, separate classes will be available for men and women, providing a supportive environment where participants can encourage one another while improving mobility and fitness from the comfort of their own homes through Zoom. Further details will be available on our website soon.

We are also finalising plans for two of our three upcoming community events, which will take place in Aberdeen, Dundee and Inverness over the coming months. These events provide a valuable opportunity for members to meet others within their local community, share experiences and take part in discussions about living with a bleeding disorder. Alongside these events, we will be inviting members to complete surveys on the issues and topics that matter most to them, helping ensure that our future projects and activities are shaped by the people we exist to support.

This year has also seen the ***Haemophilia Scotland*** team continue to grow. In June, we welcomed ***Ruth Bidoni as our new Advocacy Support Worker.*** This new role has been created primarily to help members navigate the complexities of the ***Infected Blood Compensation Scheme***, providing guidance, support and answers to questions throughout the process. As time allows, Ruth will also support members with a wider range of advocacy matters. We are delighted to have her join the team.

I am also pleased to share that our ***Financial Wellbeing Service*** will continue thanks to funding from The **National Lottery Community Fund.** This means that Maxie can continue providing the invaluable support our members rely upon, helping with benefit applications, financial wellbeing advice and wider financial support over the coming year.

Finally, I would like to recognise and thank the many members and supporters who have helped raise funds for ***Haemophilia Scotland*** over the past year. In March, Dana Ferrar took part in the Supernova Kelpies Run in Falkirk, raising an impressive £438. Mark Morris then achieved the gruesome challenge of completing two marathons within five weeks during April and May, raising a remarkable £6,371 for the charity. Dana and Mark are just two examples of the many people who dedicate their time and energy to supporting ***Haemophilia Scotland***, raising awareness and helping us continue our work. We are incredibly grateful to them, and to everyone who has supported us through fundraising, volunteering or simply by sharing our message.

I am immensely proud of everything we have achieved together over the past year and of the support we continue to provide to our community.

HAEMOPHILIA SCOTLAND

Thank you for your ongoing support of ***Haemophilia Scotland***, and I hope you enjoy reading this edition of ***The Wire.***

Female Factors: A conference for Women and Girls affected by a bleeding disorder

Our *Female Factors Conference* took place on Saturday 6th June, bringing together women and girls in Scotland affected by a bleeding disorder for a day of connection, conversation and shared experience.

From the outset, there was a real sense of openness and community, with people coming together to talk, listen and support one another.

We were delighted to welcome our guest speakers: **Dr Laura Knox, Kat Peddie from EndoSOS and Kate Little from The Haemophilia Society**, who each brought valuable insight and perspective. Their contributions helped spark thoughtful discussion throughout the day and encouraged many attendees to reflect on their own experiences and the wider challenges facing women in the bleeding disorders community.

Across the programme, there was a strong feeling of people learning from one another, finding common ground and identifying areas where change is needed. It was clear how important it is to create spaces like this, where women can speak openly and feel heard.

Guest speakers at the Female Factors Conference: Dr Laura Knox, Kate Little from the Haemophilia Society and Kat Peddie from EndoSOS

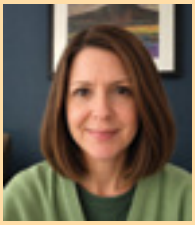
We are incredibly grateful to the Women's Fund for Scotland for making this event possible through their support. A big thank you to everyone who attended and contributed. Your voices and experiences are at the heart of everything we do.

We look forward to building on the momentum from the day and continuing to create opportunities for women and girls affected by a bleeding disorder to connect, learn and shape the future of our work together.

see also pages 5, 6 & 11

New Advocacy Support Worker role at Haemophilia Scotland

(continued from front page)



Ruth brings a wealth of advocacy experience to her role at *Haemophilia Scotland*. Having worked alongside individuals and families to help them understand and engage with different organisations, such as the NHS and social services, ensuring their voices are heard and their rights are upheld. She is passionate about ensuring people feel informed, supported and empowered throughout their journey, helping them understand their options and access the support they need.

Originally from North Wales, Ruth has always enjoyed helping others overcome challenges and access the support they deserve. Her approachable nature, combined with her experience in advocacy, enables her to build trusting relationships and provide practical, person-centred guidance.

Outside of work, Ruth loves spending time outdoors. Whether exploring the countryside, walking in the hills, or enjoying nature, she values the opportunity to recharge and appreciates the wellbeing that comes from being outside.

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'Underserved and Overlooked':

Report on improving care for women and girls with bleeding disorders

by Kate Little

Kate recently joined the Haemophilia Society (THS) as Policy Engagement Manager. One of her biggest projects is taking forward the recommendations of THS's report 'Underserved, Overlooked' and improving care for women and girls with bleeding disorders.

The report investigated the treatment and care of women and girls with a bleeding disorder in the UK and made nineteen recommendations. It found that although there are examples of great practice, women and girls often find it challenging to get a diagnosis and high-quality care and support. One of the priority recommendations THS is now working on is the monitoring and care of iron deficiency and iron deficiency anaemia.

Anaemia is when the number of red blood cells or the haemoglobin concentration in them is lower than normal, decreasing the ability of the blood to carry oxygen to the body. A common cause of anaemia is iron deficiency, where the body's iron, which is essential for producing haemoglobin, is low. Anaemia can be prevented if people are treated for iron deficiency effectively.

Anaemia is one of the top five causes of disability in women globally. It can increase risk of illness and infection and can be serious in pregnancy. With symptoms including fatigue, lack of concentration, irritability and headaches, iron deficiency and anaemia can be debilitating to live with. Women and girls with bleeding disorders are particularly at risk of iron deficiency and anaemia because of heavy menstrual bleeding (HMB).

> *"Anaemia is one of the top five causes of disability in women globally."*

Despite this, monitoring and care for iron deficiency in people with bleeding disorders is inconsistent across the UK. A study by the UK's haemophilia doctors' organisation (UKHCDO) found that clinical practices for checking iron were variable with between 25% and 100% of individuals having their iron levels checked.[1] In one group of women with bleeding disorders, 20% of iron-deficient patients did not have evidence of being treated.[2] Some women also cannot tolerate oral iron tablets or require more rapid treatment, but access to intravenous (IV) iron treatment can be challenging.

> "We will be surveying our members on their experiences of iron deficiency and iron deficiency anaemia. We hope to use the responses to shape a campaign and to inform future care."

THS is now looking to understand why this is happening and support an improvement in care. We will be surveying our members on their experiences of iron deficiency and iron deficiency anaemia. We hope to use the responses to shape a campaign and to inform future care. In addition, we are gathering best practice to share with the UKHCDO and are advocating for relevant guidelines to be updated.

In addition, THS is increasing awareness of women and girls with bleeding disorders by building a network with women's health organisations and reaching out to relevant Royal Colleges. On a government level, we are looking to plug into the women's health strategies across the UK nations and have heavy menstrual bleeding (HMB) recognised as one symptom of inherited bleeding disorders. One in five women with HMB will have a bleeding disorder, so it is essential that these women are included in conversations around care and treatment. We're proud to announce that in September we will be running an event at the Labour Party Conference in Liverpool on menstrual health to highlight the challenges women with HMB face in the healthcare system.

[1] https://pubmed.ncbi.nlm.nih.gov/41420070/

[2] https://pubmed.ncbi.nlm.nih.gov/41420070/

Addressing the needs of women and girls living with a bleeding disorder

In June, I was delighted to speak at ***Haemophilia Scotland's Female Factors conference*** about *heavy menstrual bleeding (HMB, or heavy periods)*. It was a fantastic opportunity to discuss how far we've come in understanding and treating HMB in women and girls with bleeding disorders, the challenges that remain, and why I'm genuinely excited about where we're heading next.

Where We've Been

Women and girls with bleeding disorders are disproportionately affected by heavy menstrual bleeding. More than 80% of people with Von Willebrand disease experience HMB during their lives, and for many it is the first – and sometimes only – sign of an underlying bleeding disorder. This is reflected across many different bleeding disorders.

The history of von Willebrand disease reminds us how serious this can be. The first person recognised as having the condition was Hjördis Sundblom, a young Finnish girl who tragically died from severe bleeding during her first menstrual period at just 14 years old. Thankfully, cases like Hjördis's are now exceptionally rare, but her story reminds us why recognising and treating HMB has always been such an important part of bleeding disorder care.

Traditionally women and girls with low factor levels have been thought of as not having an increased risk of bleeding and being "carriers". Yet we know many of them have been affected by bleeding, particularly HMB.

Despite progress, many women and girls remain undiagnosed. The Haemophilia Society's ***Underserved/ Overlooked*** report highlighted just how many people are still missed. Heavy periods are often normalised, making it difficult to recognise when something isn't right, and many people still feel dismissed when they seek help. Breaking the stigma around periods and improving awareness - from GP surgeries to government policy - remains essential.

Where We Are

The good news is that we now have a range of effective treatments. These include hormonal options, such as the contraceptive pill or hormonal coil, non-hormonal medicines such as tranexamic acid, and surgery where appropriate. UK guidance gives clear recommendations on investigating and managing HMB in women and girls with bleeding disorders, while also reminding clinicians to look beyond the bleeding disorder itself. Conditions such as fibroids can coexist and deserve equal attention.

One of the projects we've recently completed reviewed the care provided by Haemophilia Centres across the UK. There were encouraging findings: many centres routinely screened for anaemia and iron deficiency and offered tranexamic acid where appropriate.

However, the review also highlighted opportunities to do better. Some patients with iron deficiency had no documented iron treatment, despite iron deficiency causing symptoms such as fatigue, breathlessness and reduced exercise tolerance - even before anaemia develops.

Dr Laura Knox

Perhaps most importantly, we found that healthcare professionals are not consistently asking women how heavy periods affect their everyday lives. Managing HMB isn't just about reducing blood loss - it's about improving quality of life.

On a positive note, excellent support already exists. The Haemophilia Society's Talking Red campaign (https://haemophilia.org.uk/support/talking-red) provides practical information and advice, while Wellbeing of Women (https://www.wellbeingofwomen.org.uk) offers an online symptom checker that can even generate a personalised letter to take to a GP appointment. Small tools like these can make difficult conversations much easier.

Where We Are Going

This is one of the most exciting times I've seen in women's bleeding disorder care. At this year's *International Society of Haemostasis and Thrombosis (ISTH) Congress*, women's health and menstrual disorders featured far more prominently than ever before. There were dedicated sessions on HMB, discussions about improving services and exciting presentations on new treatments currently in development.

Change can sometimes feel overwhelming, but it doesn't always begin with major policy decisions or new medicines. Sometimes it starts with a conversation.

That's why events like *Female Factors* are so valuable. They bring together people with shared experiences, create space to ask questions and remind us that periods should never be a taboo subject. Every conversation helps make it easier for the next girl or woman to recognise that heavy periods aren't simply something she has to put up with.

It was a privilege to spend time with everyone who attended - to hear their stories, answer their questions and learn from their experiences. We've come a long way since Hjördis Sundblom, but there is still much more to do. For the first time in a long time, though, I'm genuinely optimistic. There is real momentum behind improving care for women and girls with bleeding disorders, and I'm excited to see where that journey takes us next.

Haemophilia Scotland at the SIBDN Annual Meeting

We were delighted to take part in the ***Scottish Inherited Bleeding Disorders Network (SIBDN)*** Annual Meeting in Edinburgh on Friday 21 November. The programme brought together haemophilia centre staff from across Scotland to share updates, explore new developments, and strengthen collaboration in the care of people with inherited bleeding disorders.

WOMEN'S GROUP PERSPECTIVE

Our Women's Working Group was represented by Carolyn McGimpsey, who shared powerful insights into the lived experiences of women and girls navigating both carrier status and diagnosis. Throughout her talk, she drew on recommendations from **The Haemophilia Society's SACRed Project report**, published earlier this year. Carolyn invited attendees to work with us to help address some of the key recommendations discussed. Her contribution underscored the importance of recognising and tackling the unique challenges faced by women in the bleeding disorders community, and of ensuring their voices are heard.

UPDATES FROM HAEMOPHILIA SCOTLAND

Later in the programme, Alan Martin (Director) and Maxie Cobern-Burke (Financial Wellbeing Officer) provided an update on the work Haemophilia Scotland has been leading.

This included:

- *Progress on member engagement and outreach initiatives.*
- *Ongoing projects to strengthen support for families and individuals across Scotland.*
- *Practical guidance from Maxie on how clinicians can write effective supporting letters for benefits applications, helping patients access the financial support they need.*

BUILDING CONNECTIONS

The meeting was a valuable opportunity to learn from haemophilia centre staff, hear about clinical and laboratory perspectives on new treatments, and engage with colleagues working across Scotland. We are grateful to the organisers for the invitation and for creating a space where patient voices and professional expertise come together to improve care.

LOOKING AHEAD

Haemophilia Scotland remains committed to working in partnership with the SIBDN and haemophilia centres across the country. Together, we can continue to strengthen services, improve access, and ensure that the experiences of our Scottish bleeding disorders community shape the future of care.

Young Persons Awareness Project

Earlier this year, we were working on an exciting new initiative to amplify the voices and experiences of young people living with bleeding disorders in Scotland. Thanks to funding from the Essentia Foundation, we partnered with the creative agency Four to develop a project that raises awareness, challenges misconceptions and helps young people feel seen, heard and supported.

The Young Persons Awareness Project focuses on sharing what it's really like to grow up with a bleeding disorder — from navigating school and friendships to managing treatment and the emotional impact of diagnosis.

By gathering personal stories and insights directly from young people, we're creating a series of short films and social media content that reflect their lived experiences with honesty and authenticity.

A key part of this project has been ensuring young people are involved at every stage. They've helped shape the themes, contributed ideas for filming and guided how their stories should be told. Their input has been invaluable, and their willingness to share has been inspiring.

Importantly, this project has also helped raise wider awareness of Haemophilia Scotland: who we are, what we do and who we support.

By sharing these stories publicly, we're reaching new audiences, strengthening understanding of bleeding disorders and highlighting the support available to families across Scotland.

We are now moving into the next stage of production, and we look forward to sharing the finished films with you soon. These resources will play a key role in future awareness campaigns and in helping young people feel recognised and represented.

Keep an eye on our website and social media channels for updates as the project continues to unfold.

Why I Created Project Elevate Her: Using the Seven Summits to Elevate Women's Voices

by Maia Meier

When people first hear about Project Elevate Her, they often focus on the mountains.

Over the next three years, I'll attempt to climb the Seven Summits, the highest mountain on each continent, as part of a global initiative supporting women and girls living with bleeding disorders.

It's an ambitious goal, and understandably, it's often the first thing people ask about. And that's fair. The mountains are certainly the most visible part of the project. But they're only part of the story.

As someone living with Type 2A von Willebrand Disease, I've spent much of my life navigating the realities of a bleeding disorder. Professionally, as a Clinical Exercise Physiologist, I've also had the privilege of working with individuals facing a wide range of health challenges.

At the same time, I've always been drawn to the mountains. Mountaineering has challenged me physically, mentally, and emotionally, and over the years it has become one of my greatest passions.

Project Elevate Her emerged where those two parts of my life intersected.

The more involved I became in advocacy, the more stories I heard from women living with bleeding disorders around the world. Stories of symptoms being normalized. Stories of years spent searching for answers. Stories of feeling dismissed, overlooked, or simply not fitting the traditional picture of what a bleeding disorder was supposed to look like.


'Have treatment, will travel'

Every woman's experience is unique, but many shared a common frustration: there was still a gap between what women were experiencing and the recognition, support, and care they deserved. The more I listened, the more I realized there was an opportunity to do something bigger.

I wanted to create something that could bring greater visibility to these experiences, spark important conversations, and contribute to meaningful change. I also wanted to use a platform that felt authentic to me. The mountains offered a way to do that.

Project Elevate Her was created to raise awareness, support advocacy efforts, and help accelerate progress toward earlier recognition, diagnosis, and access to care for women living with bleeding disorders. It also aims to generate funding for organizations working every day to improve outcomes for women and girls globally.

Project Elevate Her proudly supports the World Federation of Hemophilia and partner organizations around the world working to advance care, education, research, and advocacy for women with bleeding disorders.

This June, I will begin the first expedition of the project on Mont Blanc in France. Over the coming three years, the journey will span all seven continents, using each climb as an opportunity to amplify awareness, education, advocacy and fundraising efforts for women and girls living with bleeding disorders.

As I prepare for that climb, one initiative has become especially meaningful to me: the Summit Letter Series.

Women from around the world are invited to write a short message to a woman who has not yet been diagnosed with a bleeding disorder. Those letters will travel with me to the summits as a reminder that behind every statistic is a person, a family, and a story - and the hope that someone else's journey might be made a little easier.

The response has already been incredibly moving. Some letters speak about resilience. Others about frustration, hope, relief, or finally feeling understood. Together, they reflect the strength of a community that continues to advocate, educate, and support one another.

My hope is that Project Elevate Her creates more opportunities for these conversations to happen: That it encourages women to share their experiences; That it helps people recognize symptoms sooner; That it contributes, in some small way, to a

The majestic peaks of Mont Blanc in the background

future where fewer women spend years searching for answers.

Most importantly, I hope it reminds women and girls living with bleeding disorders that their experiences matter.

As I take my first steps toward Mont Blanc, those are the things I'll be carrying with me. Not just to the summit, but throughout the entire journey. Because while mountains may capture attention, it is the women behind this project, and the stories they carry, who truly deserve to be elevated.

To learn more, follow the expeditions, or support the cause, visit: www.projectelevateher.com

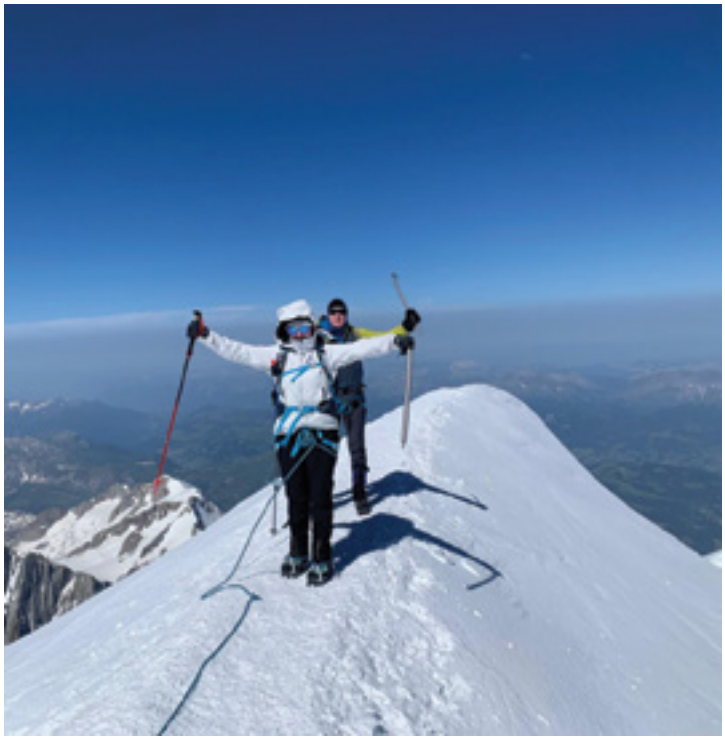
About the Author

Maia Meier is a Canadian Clinical Exercise Physiologist, mountaineer, and advocate living with Type 2A von Willebrand Disease. She is the founder of Project Elevate Her, a global initiative using the Seven Summits to raise awareness, accelerate earlier diagnosis and access to care, and improve quality of life for women and girls living with bleeding disorders.

Through Project Elevate Her, Maia aims to become the first woman with a bleeding disorder to complete the Seven Summits and the second Canadian woman to complete both Seven Summits lists and ski the Last Degree to the South Pole. The project is also working to raise $5 million in support of organizations advancing care, research, education, and advocacy for women with bleeding disorders worldwide.

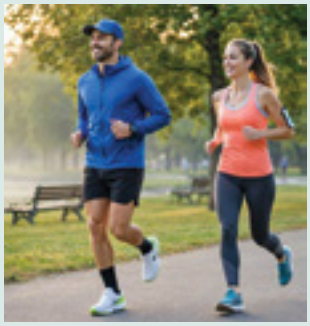
Learn more at:

www.projectelevateher.com



Feeling on top of the world

Run for us?



Whether you are an experienced runner, or seeking a new challenge to support your New Year's resolution, why not run for us and help raise awareness and funds for ***Haemophilia Scotland***?

Get in touch at ***hello@haemophilia.scot*** to explore opportunities to take part fundraising activities in 2026-2027.

HAEMOPHILIA CENTRE UPDATES

Glasgow Royal:

Gillian McNelis was appointed the new *Operations Manager* at the Glasgow Haemophilia Centre in August 2025, with *William Steele* becoming the Unit's new *Administration Support Officer* in February 2026.

We wish them both well in their new posts.

Logan is supported by his school and fellow pupils

Logan was diagnosed with a bleeding disorder when he was just six months old, after doctors noticed excessive bleeding following a routine finger prick blood test.

As Logan's mum, Lisa, explains:

"If you saw Logan, you would think he's healthy and thriving. He looks and acts just like any other 10-year-old. What you don't see is the mountain of injections, hospital visits, and days of school missed."

Despite the challenges that come with living with a bleeding disorder, Logan refuses to let it define him.

Every year, Logan's school marks ***World Haemophilia Day*** by encouraging pupils and staff to wear red and raise money for *Haemophilia Scotland*. During this time, Logan also takes centre stage at school assemblies, using the opportunity to raise awareness, educate his classmates, and share what living with haemophilia means for him.

Speaking about the support he receives at school, Logan says:

"I am happy that the school helps keep me safe when I bleed, fall, or have a cut. A health plan is kept in school, which provides clear instructions about what to do if I bleed or fall. My mum updates this whenever there are changes to my medication or health."

Logan also explains how his condition affects everyday life:

"When I am outside playing with my friends, I need to be super careful not to fall because injuries can mean I need treatment or a trip to hospital. My friends help keep me safe in school too and encourage me not to take too many risks.

When I was younger, in P1, I fell quite a lot because I was a bit clumsy and had to go to hospital several times. Now the school has medication they can give me, which helps keep me safe."

For Logan, speaking openly about haemophilia has also helped others understand the condition:

"Other children find my presentations at assemblies interesting and understand how important it is to share this information. Lots of children tell me they have never heard of haemophilia before, and I'm the only person they know with it."

The last time Logan's school fundraised for Haemophilia Scotland they raised an incredible £233.91 for the charity.

Logan, Lisa, and their school are fantastic examples of what can be achieved when educators, parents, and young people work together to create safe, supportive environments for children living with Haemophilia, Von Willebrand disease, and other bleeding disorders.

Many thanks to Logan and Lisa for sharing their story.

Susie's Story: *'A problem shared is a problem halved'*

Susie is a teacher living in the west of Scotland who speaks openly and passionately about her own experience of living with the bleeding disorder, von Willebrand Disease, in order to raise awareness and prevent other women from going through the significant traumas that have been a feature of her own life.

> ***"I simply wouldn't have coped without Haemophilia Scotland."***

Susie was diagnosed with von Willebrand at the age of 13 when her second ever period lasted for eight weeks. It was only after a second visit to a GP following profuse bleeding which soaked through bedding and clothing; weight loss; exhaustion; anxiety and six weeks off school that she was finally admitted to A&E and was given a blood transfusion, having lost 50% of her blood volume.

The transfusion immediately stopped the bleeding; which led to the suspicion of a clotting deficiency and the subsequent von Willebrand diagnosis. She was put on the contraceptive pill, which managed her periods and ensured that menstrual bleeding was controlled.

Susie is now part of the women's group at ***Haemophilia Scotland***, having become a member of our charity as an adult following traumatic bleeding experiences and treatment during the birth of her son. This has been life-changing for her, enabling her to meet other women, via Facebook, online and in-person; to hear their stories, to share hers and simply to be alongside people who know what she is going through.

Susie said: "I simply wouldn't have coped without ***Haemophilia Scotland***. I was at a really low point. What I was experiencing was sheer and utter trauma.? I was terrified about everything and anything for me and my son."

She knows that ***Haemophilia Scotland***, and her counsellor, will be there for her as she makes life choices and continues to live with a chronic and largely misunderstood condition.

Endometriosis, Endo SoS and Me

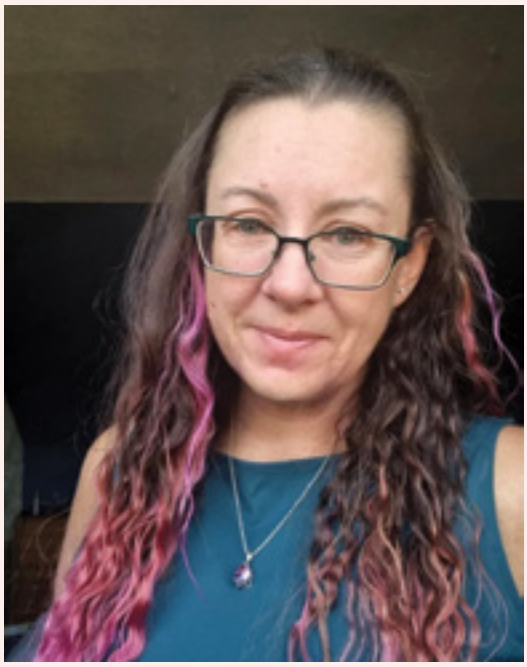
by Kat Peddie

Endometriosis has been in the news a lot recently. New tests, more awareness, more celebrities, more acknowledgement. It hasn't always been this way though, and away from the news headlines, the lived reality can be so very different from the sanitised, safe for viewing, version.

Endometriosis is a condition where cells similar to the lining of the uterus grow outside of the womb - and, outside of the pelvic cavity. Those cells respond to hormonal fluctuations around the menstrual cycle, causing inflammation, trapped blood and fatigue, nausea, increased menstrual bleeding and a variety of other symptoms. Endometriosis isn't limited to AFAB (assigned female at birth) women either, having been found in men, babies and even foetuses in pregnancy. It has been found in every organ, everywhere in the body. It is as common as diabetes with 1 in 10 women having symptoms.

> "....away from the news headlines, the lived reality can be so very different from the sanitised, safe for viewing, version."

I had my first period at twelve years old. By the age of thirteen, I knew that something wasn't right. Heavy menstrual bleeding, intense cramps and periods that lasted up to three months led me to seek advice. My GP at the time was dismissive. He wasn't the first. I was told that this was normal, that all women suffer pain, that I was being weak. By the time I was older, I was told to suck it up, get pregnant, then, that miscarriage was normal, then, that I wasn't trying hard enough. GP after GP gaslight me, dismissed my pain and other symptoms, prescribed the Pill and ignored me. It took countless appointments and changes of doctor to finally get someone to listen - and more importantly, to refer me to a Gynaecologist.



I still had to fight. The specialist was at first dismissive, but eventually put me on the surgical list for an investigative laparoscopy. It took nearly three years, from referral to surgery. This gave me the diagnosis: Extensive endometriosis - all over my pelvic organs.

> "It took countless appointments and changes of doctor to finally get someone to listen....."

Now what? I had a diagnosis of something I'd never heard of, a flimsy single page pamphlet of information, and nothing more. I was alone, and it was awful. I learnt to cope, struggling with various versions of the Pill, chemically induced menopause and lack of other support.

After having my son (a massive surprise in itself!), my symptoms returned and, this time, I got referral to Gynaecology much quicker. I had surgery in 2014 and again in 2015 and found online support and a whole community of local people with the same condition and experiences as myself. It felt powerful.

Tao McCready, the founder of the support group, had a goal that no one else go through what we had, and several of us came together and Tao founded Endo SoS as a charity. Based in the South of Scotland, we educate, advocate and support through on-line and in-person meetings, offer advice through lived experience and work with medical professionals and others to ensure voices are heard and we are not dismissed. We fight for decreased waiting times for diagnosis and surgery, raise money for new diagnostic tools and treatments, and educate medical students, doctors, and workforces.

Please reach out if you think you need us:

Website: www.endosos.org

Email: enquiries@endosos.org

Festive cheer from the Campbells

Each year, their neighbours come together for a wonderful street Christmas light switch-on, complete with a charity bake sale. This year, the Campbells hosted the event and chose to donate the funds raised to *Haemophilia Scotland*.

Thanks to their generosity (and some very tasty baking!), an amazing £290 was raised. We are so immensely grateful for this thoughtful support. These funds will help us continue our work to support, inform and advocate for our Scottish bleeding disorders community.

Thank you to the Campbells and everyone in the street who baked, donated and supported the day. What a brilliant example of community spirit at Christmas!

The Campbell family and their neighbour managed to raise a magnificent £290 in support of Haemophilia Scotland

2026 Members' Day & AGM

We are delighted to invite you to our Members' Day and Annual General Meeting (AGM), taking place at The Studio in Glasgow on **Saturday 29th August 2026**. This annual gathering is a brilliant opportunity to come together as a community, hear important updates about our work and enjoy a relaxed, familyfriendly, day with others affected by bleeding disorders.

EVENT DETAILS

Date: Saturday 29 August 2026

Time: 10:30am – 4:00pm

Location: The Studio, 67 Hope Street, Glasgow, G2 6A

What's Happening on the Day?:

- **Free Admission:** **All Haemophilia Scotland members can attend at no cost.**
- **Annual General Meeting:** **Hear key updates on our achievements, ongoing projects, and plans for the year ahead.**
- **Community Connections:** **Join group discussions, hear lived experiences, and meet others from across the bleeding disorders community.**
- **Lunch Provided:** **Lunch and refreshments will be available throughout the day.**
- **Children's Activity:** **While there is no mobile crèche this year, an arts-based activity will be offered for children during the AGM.**

Register for the event:-

Book your place at: **www.haemophilia.scot/agm2026**

We look forward to welcoming you in Glasgow!

James takes on the Bournemouth Half Marathon for *Haemophilia Scotland*

We are delighted to share that James Taberner will be taking on the ***Bournemouth Half Marathon*** on 11 October to raise vital funds for Haemophilia Scotland. His commitment to supporting the bleeding disorders community is inspiring, and we're incredibly grateful to have him running as part of our team.

James is no stranger to challenges, and this event is another brilliant example of the determination and generosity shown by so many in our community. Every mile he runs helps us continue our work to support individuals and families affected by bleeding disorders across Scotland, from providing information and advocacy to creating opportunities for connection, education and peer support.

Fundraisers like James make a real difference. The money raised helps us deliver events, produce resources, run projects, and ensure that no one feels alone in managing a bleeding disorder.

If you are able to support James in his half marathon challenge, every donation, big or small, is hugely appreciated. Your contribution will help strengthen the work we do and ensure we can continue to be there for those who need us.

Let's cheer James on as he prepares for race-day and show him how much the Haemophilia Scotland community is behind him!

Thank you, James, and thank you to everyone who donates and shares his fundraiser.

www.justgiving.com/fundraising/James-Taberner2026

Celebrating Dana's Supernova Success

We want to give a massive shout-out to Dana, who took on the ***Supernova Kelpies Run*** on the 14th March — and did it, side-by-side, with her son. They lit up the route together to raise awareness and funds for people and families across Scotland affected by bleeding disorders.

We are so grateful for their energy, kindness, and commitment to our community. Moments like this remind us how powerful it is when families come together to support others.

Infected Blood Compensation Authority (IBCA): How it could affect you?

Means-Tested Benefits and Tax Implications

The Government's update on the Infected Blood Compensation Scheme (October 2025) included the following statements:

"Compensation payments made through the Scheme will not adversely impact means-tested benefits received by people who are either infected or affected."

"Where compensation payments are awarded to an estate of a deceased infected person by IBCA and are received by estate beneficiaries on distribution of the estate, the compensation awarded will not impact on the recipient's eligibility for means-tested benefits."

The Infected Blood Compensation Authority (IBCA) website also states:

"You won't have to pay tax on your compensation, and it won't affect your benefits."

Source: https://ibca.org.uk/compensation-infected/choosing-a-single-payment-or-regular-payments

What does this mean in practice?

For people who receive compensation and are entitled to means-tested benefits such as Housing Benefit, Pension Credit or Universal Credit, these protections are important.

Normally, savings or capital between £6,000 and £16,000 can reduce entitlement to certain means-tested benefits, while savings above £16,000 will in most cases remove entitlement altogether. However, compensation received through the Infected Blood Compensation Scheme, whether paid as a lump sum or through regular payments, is disregarded as capital, **indefinitely**.

This protection applies to compensation paid to infected people, affected people and beneficiaries receiving compensation through an estate. As a result, individuals can continue to claim means-tested benefits while receiving compensation. In addition, compensation payments themselves are disregarded as income for benefit purposes.

Department of Works and Pension Example:

Stephen claims Universal Credit. He receives £20,000 from the estate of his late uncle. The money was originally paid to the estate under an approved infected blood compensation scheme because his uncle was infected through contaminated blood products.

As the payment received by Stephen is derived from compensation awarded under an approved blood scheme, the Decision Maker determines that the payment can be disregarded as capital indefinitely. Therefore, it does not affect Stephen's Universal Credit entitlement.

Income generated from compensation

Any income generated from compensation payments is also disregarded for means-tested benefit purposes. This includes bank interest, rental income and investment returns.

The disregard continues if a person later claims Pension Credit on reaching State Pension age.

It is important to keep evidence showing that any income or savings have been derived from infected blood compensation payments, as this will help ensure the disregard continues to apply. Maintaining a clear paper trail, including receipts, bank statements and other relevant records, may make it easier to provide this evidence if needed.

An Important Exception:

There is one exception to this rule. Where a diagnosed person dies without a partner or children, and compensation is subsequently paid to a parent, a person acting in place of the diagnosed person's parent, or a person who was acting in that role at the date of the diagnosed person's death, the disregard applies only for a limited period. Specifically, the disregard begins on the date the payment is made and ends two years later.

For example, Edward received compensation but never had a partner or children. When he died, he left his estate to his parents. The compensation inherited by his parents is disregarded for means-tested benefit purposes for two years from the date they receive it. Once this two-year period ends, the inherited funds may be taken into account when assessing entitlement to means-tested benefits, such as Pension Credit.

Tax and savings considerations

Compensation payments are not subject to Income Tax, Capital Gains Tax or Inheritance Tax. However, any income or gains generated from investing those payments, for example in savings accounts, shares or property, may be taxable under normal tax rules.

Your bank or building society may notify HM Revenue & Customs (HMRC) of any interest earned on your savings. HMRC may use this information to determine whether tax is due, or you may be required to report it yourself through a Self-Assessment tax return.

Everyone has a Personal Allowance set by the Government.

If your total taxable income exceeds this amount, you may be required to pay Income Tax. Certain benefits are taxable and count towards your total taxable income, including:

- *Bereavement Allowance (previously Widow's Pension)*
- *Carer's Allowance (or, in Scotland, Carer Support Payment)*
- *Contribution-based Employment and Support Allowance (ESA)*
- *Incapacity Benefit (from the 29th week of payment)*
- *Jobseeker's Allowance (JSA)*
- *Pensions paid under the Industrial Death Benefit Scheme*
- *State Pension*
- *Widowed Parent's Allowance*

You may also be able to earn a certain amount of interest on your savings before paying tax. The amount depends on your Income Tax band:

- **Basic-rate taxpayers:** £1,000 of savings interest tax-free
- **Higher-rate taxpayers:** £500 of savings interest tax-free
- **Additional-rate taxpayers:** No Personal Savings Allowance

Any savings interest above these allowances may be subject to Income Tax.

Individual Savings Accounts (ISAs) allow up to £20,000 to be saved or invested each tax year without paying tax on interest, dividends or capital gains generated within the account.

Further help

The UK Government provides online tools to help individuals determine whether they need to pay tax and how much may be due.

Haemophilia Scotland strongly recommends seeking independent financial advice before making significant financial decisions. Information is also available through the ***IBCA*** website and organisations such as Unbiased.

SCOTTISH INCOME TAX RATES 2026 TO 2027

Taxable income	Tax Rate	Band
up to £12,570	0 %	Personal Allowance
£12,571 to £16,537	19 %	Starter rate
£16,538 to £29,526	20 %	Scottish basic rate
£29,527 to £43,662	21 %	Intermediate rate
£43,663 to £75,000	42 %	Higher rate
£75,001 to £125,140	45 %	Advanced rate
Over £125,140	48 %	Top rate

Please note: This article provides general information only and should not be considered financial, tax or legal advice. Individual circumstances vary, and professional advice should be sought where appropriate.

Sources:

The Universal Credit Regulations 2013, reg 76(1)(a)(i); ADM para H2061- 1.1.b)

HB Regs, sch 6 para 24,

https://www.gov.uk/income-tax/taxfree-and-taxable-state-benefits

https://www.lloydsbank.com/savings/help-and-guidance/personal-savings-allowance.html

https://haemophilia.org.uk/support/voluntary-financial-guidance/

Help Shape Our Upcoming Events

As we plan our next programme of events, we want to make sure the topics, activities and sessions we offer truly reflect what matters to you. Whether it's an educational talk you would find helpful, a social activity you'd enjoy, or a theme you think we should explore, we would love to hear your ideas.
Your feedback plays a key role in shaping our events, and it helps us create opportunities that feel relevant, supportive and engaging for our whole community.

If you have suggestions, big or small, please get in touch. You can email us at ***hello@haemophilia.scot*** to share your thoughts.

Local meet-ups coming soon for Inverness, Aberdeen and Dundee:
We are excited to share that we will soon be getting in touch with our members who attend the **haemophilia centres in Inverness, Aberdeen and Dundee**. We are currently finalising dates and securing suitable venues, and we'll share full details as soon as everything is confirmed.

Each meet-up will include both an educational element and a social activity, creating space to learn, connect and spend time with others in the bleeding disorders community.

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

If you'd like to be involved in helping to shape or organise any of these events, you are very welcome to get in touch. Email ***hello@haemophilia.scot*** to note your interest.

There is a wide range of events and activities that could be arranged for the benefit of our members, such as, for example: *Crazy Golf; Go-Karting; Angling; Visiting the Zoo; Photography classes*, to name but a few.

Volunteering: Join our volunteer team and make a difference with Haemophilia Scotland

At *Haemophilia Scotland*, our mission is to support individuals and families affected by bleeding disorders across Scotland. As a small, dedicated, charity we rely on the passion and commitment of volunteers to make a real difference to the lives of our members. Whether you have a few hours to spare or want to take on a more involved role, volunteering with us is a fantastic way to give back, develop new skills, and be part of a caring community.

Volunteer Roles Available:

- ***Volunteer Community Fundraisers***
- ***Volunteer Content Creators***
- ***Volunteer Events Assistants***

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