



THE  
HAEMOPHILIA  
SOCIETY

## Your guide

Everything you need to know to get everyone talking about women with bleeding disorders.



**For everyone affected by a genetic bleeding disorder**

To find out more, visit [haemophilia.org.uk](http://haemophilia.org.uk) or contact us on 020 7939 0780 or at [services@haemophilia.org.uk](mailto:services@haemophilia.org.uk)

Charity no. 288260 (England & Wales) SC039732 (Scotland) UK company 1763614



HaemophiliaSocietyUK



HaemoSocUK



thehaemophiliasociety



Haemophilia Society member, Linda turned 65 on the same day as us! Here, Linda, who has von Willebrand Disease (VWD) explains why she is calling for our community to get Talking Red this June...

Hello

Thank you for requesting a Talking Red campaign pack. I hope that you have lots of fun raising much needed awareness of bleeding disorders in women.

I know from personal experience how isolating it can be having a condition that many people don't understand. And because of the rare nature of bleeding disorders, you may never meet anyone else with the same condition.

However, I feel lucky because I **know** I have a bleeding disorder and, as well as getting the treatment I need, I have the support of The Haemophilia Society and our community. It is estimated that thousands of women don't know they are affected so could be unnecessarily suffering in silence or even putting their lives at risk.

That is why Talking Red is such an important campaign for our community to get behind.

There are so many ways for you to promote awareness about bleeding disorders in women. Whether you want to hold a big red party or prefer to put up a poster in your local area, every action will help The Haemophilia Society to support more women in the future.

Thank you

A handwritten signature in red ink that reads 'Linda'.

If you would like any support with your Talking Red activities contact the Services team, on [services@haemophilia.org.uk](mailto:services@haemophilia.org.uk) 020 7939 0780

## What is Talking Red?

The Haemophilia Society's campaign to get women talking about bleeding disorders.

A bleeding disorder can be a serious lifelong condition often requiring daily treatment and specialist care. There is a lot of misunderstanding about bleeding disorders and many people don't know that women are affected too. In fact, tens of thousands of women across the UK are living with the symptoms of a bleeding disorder without even knowing it.

The **Talking Red** campaign was launched to make women more aware of the symptoms of a bleeding disorder – heavy periods, easy bruising and prolonged bleeding after a procedure or childbirth – and to promote better understanding of what it means to live with such a condition.

Bleeding disorders can't be cured but there is effective treatment available, so our message is get **Talking Red** to help the thousands of women who are suffering in silence. We need your ongoing support to reach the tens of thousands of women unaware they have a bleeding disorder and help improve the lives of those who have.

Every year we have at least one event for women with bleeding disorders. All family and friends are welcome to attend our FREE events. For more information, please check our events calendar on our website.

If you would like to fundraise for **Talking Red** please get in touch!

**Email: [services@haemophilia.org.uk](mailto:services@haemophilia.org.uk) T: 020 7939 0780 or sign up to our Talking Red Facebook Group.**

***Empowering Women  
Dispelling Myths  
Sharing Knowledge***



Did you  
Women  
can have  
bleeding disorders too.  
know?

10 % of women go to the doctor  
with heavy blood loss.

29 % of these women may  
have a bleeding disorder.

But only 2 % of these women  
get tested for bleeding disorders.

**WOMEN & BLEEDING DISORDERS**  
**#TalkingRed**

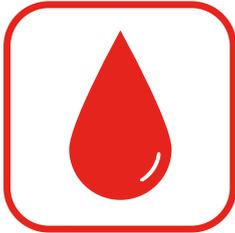
For more information please email  
[services@haemophilia.org.uk](mailto:services@haemophilia.org.uk) or call us on  
020 7939 0780



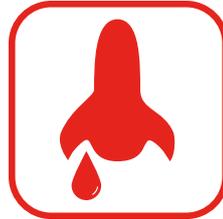
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# DIAGNOSIS QUIZ

## WOMEN & BLEEDING DISORDERS



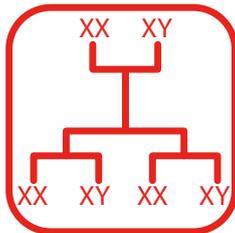
Long-lasting bleeds (after a cut, a surgery ...)



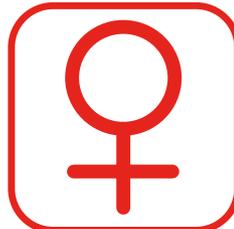
Long-lasting and heavy nose bleeds (+10 min)



Long-lasting bleeds of the gums or after a tooth extraction



Family history of bleeding disorders



Heavy and/or long-lasting (+ 7 days) menstrual bleeds



Frequent and/or large bruises



Post-partum bleed



Lack of iron, anemia



Need of a transfusion

Here are the 9 main symptoms which could indicate the presence of a bleeding disorder for you, a woman or a girl you know.

If you have ticked at least two of the boxes, please do arrange to see your GP to discuss your symptoms for a potential referral to a Haemophilia Centre for a diagnosis.

## Why we need your help

We are the only UK-wide charity for all those affected by a genetic bleeding disorder; a community of individuals and families, healthcare professionals and supporters.

For almost 70 years we have campaigned for better treatment, been a source of information and support, and raised the awareness of bleeding disorders.

36,000 people in the UK are diagnosed with a bleeding disorder and contrary to common belief more than half of those are women and the number rises every year. Access to our membership and services is FREE and open to all. We could not deliver this level of support without the generosity of our local community – people like you!

Through your support, fundraising and raising awareness of women affected by a genetic bleeding disorder you will be providing over 5,000 members with the services they deserve and need to live the best life they can.

**The money you raise will make a difference.**

***Buy your nail varnish at  
[www.haemophilia.shop](http://www.haemophilia.shop)  
today!***



## Vicky's Story

Vicky is one of only a handful of women in the country who is a haemophilia carrier and also has von Willebrand Disease. She endured very heavy periods for many years before having a hysterectomy seven years ago.

Speaking out to promote **Talking Red**, The Haemophilia Society's campaign to raise awareness among women and medical professionals about women's bleeding disorders, Vicky, 49, said her heavy periods left her feeling exhausted and weak.



Vicky was diagnosed with VWD when she was 23 and already had one child. As her father had haemophilia she was already aware that she was a carrier. Her second pregnancy resulted in a very difficult birth as a result of her bleeding disorder, after which her periods got progressively worse.

She said: **"My periods were horrific. I'd wake up stuck to the bedsheets. I'd get up in the morning and the bathroom was like a scene from Psycho. On days that I knew were going to be bad I wouldn't go out. My whole life revolved around my periods."**

**"I was exhausted all the time, I had two children and I was working. It was very difficult."** As Vicky's periods worsened she kept going to her GP to ask for a hysterectomy but was told she was too young. Finally she was given a chemical menopause 18 months before her hysterectomy at the age of 42.

Vicky said: **"I have bags more energy now than I had 20 years ago. As soon as I had my hysterectomy I've not looked back. It feels like I have my life back."**

Vicky, who believes she is one of only about 11 women in the UK to have VWD and to be a haemophilia carrier, encouraged women who are putting up with extremely heavy periods to get themselves tested for a bleeding disorder.

She said: **"If your periods are unusually heavy, go and get tested. There are things you can take that will help – such as Factor VIII or tranexamic acid. I would encourage anyone to get proper help."**

# A-Z of Fundraising Ideas

It's no mean feat coming up with ideas to raise money. That's why we have listed our favourite fundraising ideas below. If you have a great idea that isn't on the list then let us know!

## **A - Awareness #TalkingRed**

It all starts with awareness. Use our hashtags, share your photos, and use our digital resources on our website to show your support far and wide!

## **B - Bake it Red!**

Hold a bake sale! Don't forget to tag us in photos, and use the hashtag #BakeItRed (Cheating and buying cakes is allowed!!) You could also hold an online baking class and charge people to join.

## **C - Coffee Morning**

Coffee mornings bring the community together for a great cause. Entry fee could include a drink and biscuit. You could also play our Talking Red quiz!

## **D – Dance challenge**

Hold a danceathon at home! Pick a time, get your favourite tunes ready and ask people to sponsor you. Post pictures and videos online or stream it live. Wear red and use #TalkingRed hashtag to get more people involved.

## **E – Endurance challenge**

Get sponsored to test your abilities. Do a bikeathon, hold a plank, or try to reach a new personal record in squats or skipping.

## **F - Fancy dress & face paint**

Dressing up isn't just for Halloween! Hold a fancy dress contest at work or school, perhaps with a dash of #wearRED with red lipstick or red trainers, or even a red wig!

## **G - Give up something**

Here's an incentive to kick the habit – whether it's chocolate, cigarettes or alcohol that's your vice, give it up and donate the money you would have spent to us!

## **H – Hour of your pay**

Ask your friends and family to donate an hour's worth of their salary on payday.

## **I – Indoor fundraising**

Most fundraising in the current situation must be done indoors and you can get very creative with that. Have you picked up any new 'lockdown hobbies' that you could get sponsored to do? Or you can clear out your wardrobe and sell things you don't use on Depop, eBay or any other online shops.

## **J – Jar collection**

You can collect spare change in a jar and once it's full deposit the contents into our bank account!

## **K – Knitting**

A Knit-a-thon can be a fun way to raise some money for Talking Red. You can ask people to sponsor you, knit hats and scarves to order for your friends and family, or knit something and auction it. Remember to include some red yarn!

## **L – Lunch and learn**

Set up a time for people to meet and learn over lunch. You could talk about a specialist subject or share skills such as knitting, cooking or photography. You can all connect via an online platform and enjoy lunch while learning new skills.

## **M – Miles at home**

Set yourself a target to complete a certain number of miles or steps in a certain amount of time. You can set yourself daily, weekly or monthly target, which will keep you active even with new restrictions.

## **N – Non-uniform/dress code day**

Ditch your uniform or office clothes for a day and wear red loungewear instead. Get others in the office or school involved and charge a small fee to everyone involved.

## **O – Odd job**

Help your neighbours and friends with those odd jobs around the home or garden. Pick up shopping, walk the dogs or do some DIY for a small donation. This could be really helpful, especially if they can't do it themselves due to self-isolation.

## **P - Paint It Red!**

Paint your pinkie nail red, to start a conversation about women affected by genetic bleeding disorders. Take a picture of your red nail, post it on social media and nominate three people to do the same! Use our hashtags #PaintItRed #TalkingRed and our text donation code TalkingRed70085.

## **Q – Quiz night**

Ask your friends and family to pay an entry fee and set a small amount as a prize. You can find questions online and tailor them around women and bleeding disorders or use our bespoke Talking Red quiz.

## **R – Raffles**

Ask friends, family and local business to donate small prizes and get people to take part in an online raffle!

## **S – Sweets**

Get people to guess how many sweets are in a jar for a small fee. The closest guess wins the sweets. You can play the game at online meetings, schools or offices.

## **T – Talent show**

Get friends, family and colleagues together for a talent show. You can either prerecord videos and share them or stream it live. Ask for donations to take part and set up a JustGiving page to share videos with a wider audience to increase donations.

## **U – Upcycle**

Get crafty and create sock puppets, key holders, jewellery, or even cook candles. Use materials you find around the house, post videos and pictures on social media and sell them to your friends, family or wider audience.

## **V – Virtual book club**

Take your book club online or set up your own online book club and donate the money that you would have spent on drinks and snacks.

## **W - Wear It Red!**

The possibilities are endless! You could wear red in the office as a whole team, challenge yourself to wear red for a month, or hold a non-uniform day at school - tell everyone to #WearItRed for every woman affected by a genetic bleeding disorder!

## **Y – Yoga**

If you are a self-confessed yoga bunny you could host an online class and ask for a small donation to take part. Or you could search online for yoga routines to help you stay fit especially if you're still working from home, and donate money you would have spent on a yoga class.

## **Z – Zumba**

If yoga is too slow paced for you, why not try Zumba? Again, you can decide between hosting a class or finding routines online and donating what you would otherwise spend on a class to help us raise awareness and bring some real change into lives of women with bleeding disorders.

# How to plan your event

We've created a handy little questionnaire that should get your creative juices flowing:

## What will your event be?

What type of event do you want to run? Can you cash in your skills? e.g. are you a gym freak or a star baker? Theme your event along lines that suit your personality. Have you run an event before that was a success? Do you fancy the challenge of doing something new altogether?

## Where will your event be?

Do you need a venue for your event or could you run it at home? Do you need a space at all? Will it be inside or outside? If you require a venue is it licensed to host the number of people you plan to invite? Can you bag a free venue from your connections? Do you need to comply with any laws or hire any equipment?

## When will you hold your event?

If your event is outdoors, remember British weather and plan for the worst. If there are events going on in your area consider becoming part of one e.g. requesting a stall rather than starting from scratch. Many council websites list their community events publicly. If you are inviting friends and family, try to work around birthdays, holidays and school commitments. Avoid clashing with any wider events such as cup finals, particularly if you want your event to have wider appeal to the general public.

## Who will join your team?

Organising an event can be a lot of work, so we don't advise to do it alone. Who do you know who might like to join your team? Who would you like to invite and where can you approach them to tell them all about your fundraiser? Are you keeping it to friends and family or the public too? Can family, friends and local businesses join forces with you to sponsor you or provide freebies like food, drink and raffle prizes? Could you reach out to a journalist in your local paper to photograph and write up your event?

## How will you make it all happen?

Planning can be fun, we promise! Use your calendar to work out how long you have before your event and allocate tasks and deadlines for all the things that need to be done. Be realistic in setting expectations. How will you cover the cost of your event and still turn a profit? Think of other ways to fundraise that combine well – for example you could run a raffle during the break at a pub quiz. How can you promote your event using social media, local press and radio, and posters in local shops & services? Try to wangle as much free or discounted stuff as possible!

## Keep it legal

Make sure you stay above board when it comes to rules and regulations.

### Health and safety

Take precautions to hold a safe event. If you are organising a large scale or physical event you will need to make sure that you have first aid cover. Organisations such as St John's Ambulance ([www.sja.org.uk](http://www.sja.org.uk)) or the British Red Cross ([www.redcross.org.uk/first-aid/get-first-aid-cover-for-an-event](http://www.redcross.org.uk/first-aid/get-first-aid-cover-for-an-event)) can help you to decide the type of cover you'll need.

Venue - Don't exceed maximum venue capacity. Check with the venue whether they have insurance which covers your event - you may need to apply for public liability insurance. Risk Assessment. Does the venue require you to complete a risk assessment before the event? Ask them to advise you on this.

### Food hygiene

Take care when handling food to follow basic food preparation rules. If you're supplying food, think about what ingredients are used. Some people may have allergies to certain foodstuffs so you'll need to be able to let them know if they need to avoid certain foods.

### Promotion

When promoting our event please make sure that you use the poster which includes our logo and registered charity numbers.

### Raffles, tombolas & collections

If you are collecting money in a public place local to you, check first with your local council as you may need a licence. Collections on private property won't require a licence but you will need permission from the owner, for example, asking the store manager of your local supermarket, if you would like to collect in their store or car park.

### Legalities

If you need any further advise on any of the rules and regulations you may need to follow, please get in touch at [fundraising@haemophilia.org.uk](mailto:fundraising@haemophilia.org.uk)



The Haemophilia Society cannot accept any responsibility for your event or anyone who participates in it.

## How to pay in the money you raise

Thank you for fundraising for The Haemophilia Society. There are several easy ways to pay in the money you raise.

### Online

Go to [haemophilia.org.uk/donate](https://haemophilia.org.uk/donate) or phone 020 7980 0870. You can also make a BACS transfer by contacting [fundraising@haemophilia.org.uk](mailto:fundraising@haemophilia.org.uk)

### By post

Send a cheque made payable to 'The Haemophilia Society' along with your paying in slip to:  
The Haemophilia Society  
52b Borough High Street,  
London  
SE1 1XN

**Please do not send cash!**

### Other ways you can support us

Thank you so much for your interest in fundraising with us. It's a fantastic way to support us but it's not the only way. It's also possible to:

- Give a one off donation online or through the post
- Set up a regular gift – arrange a monthly donation through our website
- Take part in one of our challenge events – we have places at lots of running, walking and cycling events
- Remember us in your will and leave a legacy





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### Your Society: getting in touch

The Haemophilia Society  
52b Borough High Street  
London SE1 1XN  
Phone: 020 7939 0780  
Email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)  
Web: [haemophilia.org.uk](http://haemophilia.org.uk)

 [HaemophiliaSocietyUK](https://www.facebook.com/HaemophiliaSocietyUK)

 [HaemoSocUK](https://twitter.com/HaemoSocUK)

 [thehaemophiliasociety](https://www.instagram.com/thehaemophiliasociety)

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President: Baroness Meacher

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