



THE
HAEMOPHILIA
SOCIETY

Your campaign 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 or contact us on 020 7939 0780 or at services@haemophilia.org.uk

 HaemophiliaSocietyUK

 HaemoSocUK

 thehaemophiliasociety

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



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 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.

We are now in the fourth year of **Talking Red**, and thanks to the fantastic support of women across the country we have spread the message right across the UK, but we have lots more to do. **Talking Red** is growing every year so please join us in raising awareness of women with bleeding disorders.

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!

services@haemophilia.org.uk
020 7939 0780

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

*Did you
Women
can have know?
bleeding disorders too.*

**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.**

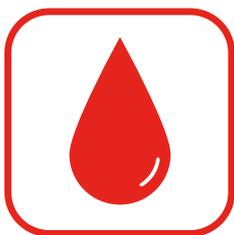
WOMEN & BLEEDING DISORDERS

#caughtredhanded

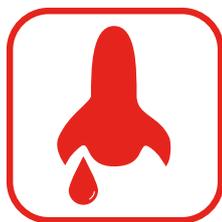
#TalkingRed

DIAGNOSIS QUIZ

WOMEN & BLEEDING DISORDERS



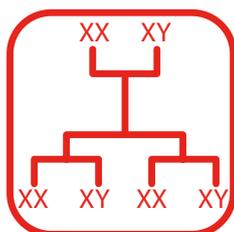
Long-lasting bleeds (after a cut, a surgery ...)



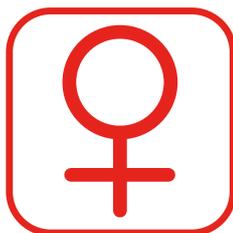
Long-lasting and heavy nose bleeds (+10 min)



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 checked at least two of the boxes please do seek counselling and set up an appointment with a physician specialised in hematology or at your local hospital in order to determine if you are a person with a bleeding disorder.

How can you promote Talking Red?

#WearItRED #PaintItRED

Every year, #TalkingRED gets bigger and bigger and the fight for equality, to raise awareness of women with bleeding disorders gets closer to its goal of understanding by all.

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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.

How can you do your bit?

We need you to help spread the word.

We need you to tell people that women also have bleeding disorders, to help women become more aware that they could have a bleeding disorder

#PaintItRed

Get everyone you know to paint their Pinky RED – starting on the Sunday of #TalkingRED week, ask friends to paint their nail and tell people why.

The best people to do this are the guys, its not something they would normally do – and people will ask them why. Make sure they have the Q&A sheet to answer questions.



Feel like taking it to the next level –
#PaintItRED 5 for £5

Get your friends to paint a nail a day on one hand and sponsor it for £1. By the Friday they will have a beautiful set of red nails and £5+ to help us raise more awareness. Maybe they could get friends to sponsor them too!

Nominate three friends on Twitter (men and women) and ask them to take on the 5 for £5 challenge.

Have you bought your red nail varnish yet? – buy it here today and support our work
www.haemophilia.shop

#WearItRED

Want to go to the next level?

Why not get everyone to **#WearItRED**

During **#TalkingRED** week, get your work colleagues, friends, family and anyone you can think of to have a day where they all dress up in red. They could all pay £2, but by doing it and spreading the word, you will help raise awareness.

Imagine going into work and your team and colleagues are all in red. Red wigs, red clothes, maybe even red face paint.

How to make the most of #PaintItRED and #WearItRED?

Get onto social media, tell the world.

Use the photos on Facebook, Twitter, Instagram and use the #Hashtags - **#PaintItRED**
#WearItRED **#TalkingRED**

Link to our website for people to find out more www.haemophilia.org.uk/talking-red/

Ask your friends to like and share posts, get them to spread the word.

You can also share and re-post our articles and stories – keep an eye on our pages.

Need some more help? Get in touch!!!



Janet's Story

Despite experiencing very heavy periods, the trigger point for diagnosing Janet's bleeding disorder was when she had her wisdom teeth extracted.

Twice, aged 19 and 23, Janet experienced haemorrhages after wisdom teeth were taken out which resulted in a diagnosis of Type 1 von Willebrand Disease. As far as she knows, she is the only person in her family to have the condition.



Now 60, Janet remembers being told by doctors to go to the library to read up about it, and left hospital with no understanding of VWD at all.

Speaking to promote **Talking Red**, The Haemophilia Society's campaign to raise awareness among women and health professionals about women's bleeding disorders, Janet said she felt alone after her diagnosis and found it very difficult to cope with her heavy periods. Janet was on a 60 day-cycle and would haemorrhage for the first 12 days – making it very difficult to maintain her career and social life.

She said: **"When I was due on I wouldn't go out. I was too embarrassed to go out. My periods affected my whole life – everything was driven by the calendar. I didn't have the guts to commit suicide, but that's how low I felt. I couldn't cope with it."**

Janet was permanently anaemic as a result of her heavy bleeding, which meant she was also exhausted.

She was put on medication which stopped her periods for many years and enabled her to lead a more normal life, although she continued to have health complications as a result of VWD. Aged 43, after the discovery of five large fibroids in her womb, Janet had a hysterectomy.

Janet said: **"The hysterectomy gave me my life back. I felt better and healthier – I could do simple things like plan holidays again."**

From her experience of living with a bleeding disorder, Janet believes more must be done to educate the medical profession. She said: **"If someone goes to their GP because of heavy periods, they need to listen and not just dismiss them. They need to investigate why. I've got a good GP, but she doesn't understand VWD – she asks me questions and I feel I'm educating her."**

"For any woman who is worried about their periods, I would encourage them to persevere, to keep pestering their GP and if necessary to ask straight out to be tested for VWD. "Things have thankfully changed since I was diagnosed. I wouldn't want any girl to go through what I went through."

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."**

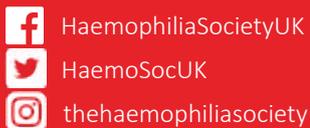


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Your Society: getting in touch

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