



# A campaign for carriers and women with bleeding disorders

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## Introduction and objectives:

The UK Haemophilia Society identified the need to develop services and information for carriers and women with bleeding disorders, as an area which was lacking in provision. The objectives are to widen awareness, provide much enhanced support and increase knowledge not only among the general public but also with healthcare professionals.

## Materials and Methods:

Since 2014 The UK Haemophilia Society, through working with a group of carriers and women with bleeding disorders, has developed a deeper understanding of the issues women encounter. We have identified specific areas requiring support as well as the need for tailor-made information and services. To this end we launched a campaign called 'Talking Red' to encompass all women's services. Some of the work The UK Haemophilia Society has carried out or is currently undertaking for the Talking Red campaign comprises:

## Information:

- Creating awareness of symptoms: heavy periods, bruising easily and prolonged bleeding after a procedure or childbirth
- Information on genetic testing and genetic counselling
- Information for male partners to enable them to feel more confident when supporting their partner or children with a bleeding disorder
- Information on family planning including issues such as not being able to have children

## Spreading Awareness:

April 2015 – Carried out a radio campaign around bruising and associated misconceptions

August 2015 – Explored women's issues at an Arts weekend through art, dance, drama and song

During 2015 – Enrolled two female Youth Ambassadors, both with vWD, who are effective spokespeople and advocates for this cohort



## Talking Red Campaign

January 2016 – Brought 60 carriers and women with bleeding disorders along with expert speakers together at a Talking Red Conference

## Key messages from the Talking Red Conference:

- Women should register with a Haemophilia Centre
- If a girl's father has haemophilia, test the girl before her periods start
- Women should have genetic testing before they get pregnant
- Have physiotherapy
- Exercise
- Eat healthily
- Access psychological support for improved mental wellbeing
- If a heavy period affects quality of life then it is an issue and must be addressed
- Haemophilia Centres should build a good relationship with carriers
- Girls with severe bleeding disorders should have a health care plan

June 2016 saw the Talking Red campaign reach out even further, including the creation of a Talking Red information pack for women members to share in their local communities. 2016 sees Talking Red groups being set up at four universities across the United Kingdom; providing a forum where young women can find peer-support and information. The aim is that eventually every university will have a Talking Red group.

**Results:** With the Talking Red campaign growing from strength to strength, women are coming to realise that the UK Haemophilia Society is an authoritative and welcoming place to find information and advice on issues that really matter to them. As a result, there has been an increase in membership of women with a bleeding disorder of over 40% since 2014.

**Conclusions:** Supporting women through the Talking Red campaign is an essential tool in support of all people with a bleeding disorder. Because every person with a bleeding disorder, whether haemophilia, Glanzmann's or vWD, will have mothers, sisters, aunts, wives or partners whose wellbeing can only benefit everyone in our community!



THE HAEMOPHILIA SOCIETY

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