# Diagnosis Quiz

Women & Bleeding Disorders

# $\checkmark$ 2 or more $\rightarrow$ see a doctor, get tested for a bleeding disorder



These **9 main symptoms** could indicate the presence of a **bleeding disorder**.

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.

## **Action strategy**

support for WBD

- (1) Get in touch with your **local NMO**. Full list of patient groups on **www.ehc.eu/membership**. Join the network, become a member.
- 2 Get to know the **board** and other **volunteers**, their **activities** and see if there is anything specifically for women with bleeding disorders.
- 3 If the NMO is not doing anything specific then reach out to the **EHC Women's Committee**. See contact information below.
- 4 Get together with **other women** and find out what you **need**. Establish a clear **plan**. How will you achieve it? Present it to your board.
- 5 Keep in mind that the EHC offers many training opportunities as well as scientific conferences where you can get more information about women and bleeding disorders. The EHC also offers activity grants to their NMO for projects that need a little extra help to get started. Go to the next page to find out more!



### European Haemophilia Consortium

**www.ehc.eu** facebook.com/europeanhaemophiliaconsortium twitter.com/EHC\_haemophilia

### **Women and Bleeding Disorders Committee**

**EHC staff support** is Laura Savini laura.savini@ehc.eu



## Look inside to find out why a **Women's Committee** is important.



Start Do you have a Women's Committee in your National Patient Organisation (NMO)?

1.

Yes

Congratulations, you are doing great! Don't forget to **share your experiences** and best practices with other organisations! That's ok ... Go to number 2.

No

#### Representation

2.

If you feel like **women's issues** are already being addressed within your NMO, a Women's Committee is not always necessary.

Does your NMO have female board members who represent women's issues?

Yes

Your NMO is clearly taking into account women with bleeding disorders. We still want to encourage you to **connect** with **other women** across Europe. If you feel like your NMO could do more, then we advise you to go to 3.

#### **Yes** You are way ahead of

most other countries and you should **showcase your experience** with others.



Then let's go to 4 to see whether your NMO needs a Women's Committee.

#### Yes

We are so glad to hear that! Bleeding disorders can really **impact** mental health and wellbeing and having a **safe space to talk** about issues is an integral part of your care.

#### No

Remember you are not alone! There are thousands of women in Europe in the same situation as you. **Reach out** to your NMO or us to connect: **ehc.eu** 

#### 5. Support

Many women with bleeding disorders often feel **lonely** and **isolated**.

Talking about intimate things such as **periods, fertility and self-esteem** can be often difficult, especially to those who may not be affected by a bleeding disorder.

Do you feel like you have a safe space and support group to which you can freely talk about all of this stuff?

Yes

It sounds like you may need to take some action. But hang on, let's go to question 5 to check one final thing ...

# → No

Then let's go to 3 to see whether your NMO needs a Women's Committee.

3.

**Awareness** 

In our experience, women

with bleeding disorders are often

'invisible'.

They are not shown in national

statistics and are not known by

haemophilia treatment centre. However

they also experience serious bleeding

events (see the diagnosis card overleaf).

With all this in mind do you feel like

women with bleeding disorders

are well represented in your

country?

### Recognition

4.

Women's bleeding symptoms are very often **'ignored'** by healthcare professionals.

This is because bleeding is seen as 'normal' in women.

Take a moment to think if you struggle to be taken seriously by a medical professional when you present yourself with a bleeding symptom?

No

That probably means that you are already visiting a specialised **haemophilia treatment centre** (HTC).