

Female Factors survey 2021

Suzanne O'Callaghan

In August 2021 HFA undertook an evaluation survey of our two young women's education resources - *Female Factors - information for young women with bleeding disorders* and *Sport and exercise for girls and young women with bleeding disorders*. We are working on the next The Female Factors resources and want to understand what has worked well and what improvements to make in the future.

These resources are part of the HFA women and girls The Female Factors project. The project is developing specific information resources for Australian women and girls affected by bleeding disorders to:

- **Increase their understanding of their bleeding disorder**, treatments and strategies to manage it
- **Help them to feel more connected** with each other by sharing personal stories and tips with others in similar situations
- **Develop high quality, evidence-based information** that they can show to other doctors, nurses, dentists, physiotherapists, etc who provide their care.

WHO COMPLETED THE SURVEY?

We only had a small response, but their answers provided valuable insights. Our thanks to everyone who did the survey

26 people (**24 female/2 male**) completed the survey

From all states except ACT and NT
(1 did not say where they lived)

62% had haemophilia or carried the gene, 27% had VWD, others had rare clotting factor deficiencies, inherited platelet function disorders or acquired haemophilia, or were parents.

12% were **18-30 years of age**
38% were **31-44 years of age**
50% were **45 years and over**

Most had a bleeding disorder or carried the gene.

20% were parents; 27% were family/friends; 8% had a professional interest.

WHICH RESOURCES HAD THEY SEEN?

96% had seen **Female Factors: Information for young women**



- Information about bleeding disorders in females for young women
- Working with HTC's and other health care practitioners
- Personal stories

35% had seen Sport and exercise for young women



- How young women with bleeding disorders can best participate in sport and exercise
- Managing risks, periods, dealing with injuries
- What to tell your coach or club

23% had seen the print version

65% had seen the HFA website version

8% had seen the Factored In website version

31% had seen the online PDF version

WHAT DID THEY THINK OF THE RESOURCES

63% thought they were very or extremely useful

75% thought the design and layout was very good or excellent

61% thought the stories and tips were extremely or very valuable.

What did they like?

- Easy to read, age appropriate, informative
- Attractive design
- Specifically about females, explained the difference to the male experience
- Feel more connected with stories

What could be improved?

- Promote the resources more
- More variety in the images
- Shorter and longer versions for diverse readership
- Handbag size.

'I think the information was great. Not sure if needed improving at this point.'

'Age appropriate, not condescending.'

'Easy to read and comprehend. It helps me to feel validated in my life experiences with the disorder. Knowing there are other people particularly women experiencing the same things.'

'They provided a simple explanation for things. I really appreciated the inclusion of the information that women can have haemophilia despite having 2 X chromosomes. I have been told so many times by doctors who know nothing about bleeding disorders that I don't have haemophilia because I am female even though my levels are lower than my Dad's who is a Mild Hemo.'

'Diversity, make sure women of all shapes and sizes, heritage and beliefs are represented in the photos.'

'We should be proud of these resources and use them as much as possible.'

'Next stage to have some interactivity... social media posts by topic driving access to specific sections of the publication, then a link back to socials to start a conversation/sharing.'

WHAT DID THEY DO WITH THE RESOURCES?

50% had passed these resources on to others – health professionals, family/friends, colleagues

Why? To educate them

'They didn't know there were updated resources produced for women/girls.'

'It was relevant to my family - my niece carries the gene.'

'To help educate people it's not just males that have haemophilia.'

'To educate my mother, the grandmother of a girl with haemophilia, to give her more of an understanding about the condition in black and white.'

WHAT'S NEXT?

HFA is working on the next two resources for *The Female Factors* project:

- Haemophilia testing in females – factor level and genetic testing
- Family planning, pregnancy and birth.

We are using the feedback to develop the content and layout:

- Short/simple and longer/more detailed versions of the haemophilia testing resource
- The short and simple version will be handbag size (A5)
- Designed as an education tool both for women with bleeding disorders and their families and for others who are new to bleeding disorders
- Continuing to include personal stories and quotes.

Promoting the resources is essential:

- Linking resources more visibly on the HFA and Factored In websites
- Investigating new ways to promote the resources on social media.

And we are always looking for women, teenage girls and parents of girls who are interested in contributing to the content with ideas or personal stories or reviewing drafts of the resources.

If you would like to be involved, contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au

T: 1800 807 173

Suzanne O'Callaghan is HFA Policy Research and Education Manager

What to have in your first aid kit

- Your regular treatment, or the treatment for an injury in your treatment plan
- Emergency contact number
- Crepe bandage and padding
- HTC contact details/ ABDR patient card.
- Tissues
- Band-aids
- Ice pack

If you experience any bleeding from engaging in sport or exercise:

- Undertake first aid including P.R.I.C.E. (protection and product, rest, ice, compression, elevation). This reduces swelling and joint and muscle pain.
- Follow up with your HTC for guidance on rehabilitation and returning to exercise.
- If it is a musculoskeletal injury, most HTCs will have a physiotherapist attached to the Centre who can give specific advice.



Other things to think about

- Many of the sports supplements have ingredients that are not recommended for bleeding disorders. Before you take a supplement, talk to your specialist doctor (haematologist) or pharmacist about what to be cautious with or avoid.
- You can meet other girls and young women with bleeding disorders through your local Haemophilia Foundation – a great way to share tips and experiences and just have fun together.



Any questions?

If you need more information or support, contact your local Haemophilia Treatment Centre.

You can find contact details of Haemophilia Treatment Centres around Australia on the Haemophilia Foundation Australia website.

For more information about bleeding disorders, or how to get in touch with your local Haemophilia Foundation or a specialist Haemophilia Treatment Centre, contact:

Haemophilia Foundation Australia (HFA)
T: 1800 807 173
E: hfaust@haemophilia.org.au
W: www.haemophilia.org.au



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