COMMENTS AND SUGGESTIONS

'A lot of information - all in the one place!'

'Clear concise correct information that you can trust is so important.'

'It just doesn't have that WOW factor.'

'It is a great initiative. For obvious reasons, much info is directed to children and now we are living longer, there needs to be more info re older living with haemophilia.'

'It is a collated area with lots of important relevant information for aging haemophiliacs. Instead of trying to find all of the information myself, it is presented there with no digging required.'

'Easy to access and to navigate around the site. It has real people talking about their conditions.'

'Older people talking about treatment before it became easier, the joint damage and viruses, that it is not just me.'

'Maybe some lighthearted topics, such as "things to do with the grandkids that don't require much physical activity". Include something that would get people to bookmark and visit the page on a regular basis like an interactive recipe hub or weekly puzzles.'

'Made me reflect - feel old - sad - seeking someone to talk to is important.'

'Made me think about contacting my HTC about worsening joint damage and planning for surgical options in the future. Also to talk to my employer about a more ergonomic setup for me at work (office) to avoid my joints locking/ becoming stiff.'

WHERE TO NEXT?

It was very helpful to hear from community members about the topics where they would like more information and that they would like more personal stories. We have added them to our content development schedule.

We took very seriously the comments about needing a more dynamic and life-affirming look and feel and content on the Info Hub. The concept of the Info Hub is about living well into the future as you grow older and the structure, images and topics on the Info Hub will need to promote this. We are already looking into some options, both in the short term and the longer term. More soon!

Our thanks to everyone who completed the survey.

Visit the Getting Older Info Hub at
www.haemophilia.org.au/getting-older

Suzanne O'Callaghan is HFA Policy Research and Education Manager

Rare Disease Day 2022

Rare Disease Day is celebrated worldwide on 28 February to raise awareness about the experiences of people with rare diseases.

The 2022 theme of **Rare is many. Rare is strong. Rare is proud** reminds us how important it is to come together and connect as a community. This is an opportunity to share personal stories and acknowledge the challenges for our community members who live with a rare disorder.

WHAT IS A RARE DISEASE?

In Australia, a disease is considered rare if it affects less than 5 in 10,000 people.

Around 8% of Australians (2 million people) live with a rare disease.

About 80% of rare diseases are genetic.[1]

Haemophilia is considered rare.

Approximately:

- 1 in 6,000 males has haemophilia A
- 1 in 30,000 males has haemophilia B

Researchers are still gathering data on how many females are affected by haemophilia.

Some bleeding disorders are very rare.

For example, factor X (10) deficiency only affects 1 in a million people.

Type 3 VWD is the rarest form of von Willebrand disease, occurring in 1 in 1-2 million people in countries like Europe and the USA.[2]

PERSONAL STORIES

In Youth News in this issue of *National Haemophilia*, Adam tells his story of raising awareness about haemophilia in his local community and school. He explains why it is important and how it helps the people around him support him, both in emergencies and in his everyday life, and not try to make decisions for him.

You may have seen some other personal stories about living with very rare bleeding disorders on our social media platforms in the lead up to Rare Disease Day:

- **Belinda's story (factor X deficiency)** - https://tinyurl.com/FI-Belinda
- **Simoni's story (VWD type 3)** - https://tinyurl.com/FI-Simoni

Our thanks to Adam, Belinda and Simoni for sharing their personal stories.

Sharing personal stories is an important way to help people with rare diseases feel connected. It can also help the wider community to understand better what it is like to live with a rare disease.

Many people with rare diseases speak of feeling isolated. Many have never met or heard of another person with their condition. If they are the first in their family with the condition, or have a very rare combination, like two bleeding disorders, it may have taken a long time for them to be diagnosed. Women and girls with haemophilia also talk of not being believed because of the common assumption that only males have haemophilia.

TREATMENTS

Treatment development is another issue for very rare diseases. When rare diseases are very rare and numbers are small, this can mean that the development of new and highly effective treatments is slow. There may even be no treatment that specifically targets that condition. For example, while there has been great excitement around the world about the novel therapies developed for haemophilia and the difference they make to reducing bleeds and quality of life, there is not yet a specific clotting factor concentrate that is suitable to treat factor V (5) deficiency and fresh frozen plasma may be used for treatment instead.

HOW CAN YOU HELP?

You can help to raise awareness by sharing the stories of people with bleeding disorders through your personal networks.

Perhaps you have a story you would like to share yourself? Visit the SHARE YOUR STORY section on the HFA website to tell us more about your story - www.haemophilia.org.au/shareyourstory

RARE DISEASE DAY®

For more information on Rare Disease Day. visit www.rarediseasedayaustralia.com.au

REFERENCES

1. Australian Government. Department of Health. What we're doing about rare diseases. https://www.health.gov.au/health-topics/chronic-conditions/what-were-doing-about-chronic-conditions/what-were-doing-about-rare-diseases Accessed 15 February 2022

2. Orphanet: the portal for rare diseases and orphan drugs. https://www.orpha.net/ Accessed 15 February 2022