## CONTENTS

- 3 From the President
- 4 World Haemophilia Day 2020
- 7 Let's talk about getting older
- 15 Physiotherapy and Bleeding Disorders during COVID-19
- 18 Surviving and Thriving in Times of Pandemics
- 23 News from South Australia \_\_\_\_\_\_
- 24 When Life Changed with Inhibitors – Christopher's Story
- 26 Youth News
- 28 Calendar

Haemophilia Foundation Australia Registered No.: A0012245M ABN: 89 443 537 189 7 Dene Avenue Malvern East, Victoria, Australia 3145 Tel: +61 3 9885 7800 Freecall: 1800 807 173 Fax: +61 3 9885 1800 hfaust@haemophilia.org.au www.haemophilia.org.au Editor: Suzanne O'Callaghan



## **PROBE STUDY**

## Do you have haemophilia or carry the gene?

Have you completed the **PROBE** (Patient Reported Outcomes Burdens and Experiences) questionnaire?

The survey is available at <a href="https://tinyurl.com/PROBE-Australia">https://tinyurl.com/PROBE-Australia</a>

Or ask HFA or your Foundation for a print copy.

Your responses can help to build strong evidence about the impact of haemophilia.

PROBE is a multinational study where Australians can give evidence about living with haemophilia and the impact of different sorts of treatment on their bleeds, pain and quality of life.

HFA will use the data to better understand current issues - and this data is crucial for our treatment advocacy.

You are invited to complete the survey if:

- you are an adult with haemophilia or carry the gene
- or you are an adult and DON'T have a bleeding disorder (as a comparison group)

Consider being involved to help us with this important study!

## **ANY QUESTIONS?**

For more information about PROBE in Australia, visit www.haemophilia.org.au/research/probe-study

Or contact Suzanne at HFA: E: socallaghan@haemophilia.org.au T: 1800 807 173

