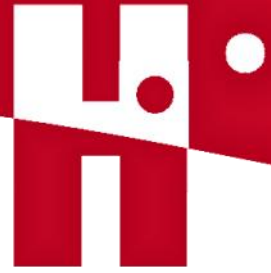


# CONTACT

Newsletter of Haemophilia Foundation WA Inc.

June 2024



# World Hepatitis Day 28 July

Cover Picture: World Hepatitis Day Logo 2024

The Management Committee thanks everyone who got out and about to take the WHD photos and share on social media. Stock images sourced from pixabay.com unless otherwise noted. Permissions granted by those in featured event pictures and the photographers of images.

**HAEMOPHILIA FOUNDATION WA INC.**

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HFWA proudly acknowledges our Patrons,

**His Excellency The Honourable Chris Dawson AC  
APM**

**Governor of Western Australia  
and Mrs Darrilyn Dawson**



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## YOUR COMMITTEE 2023/2024

Gavin Finkelstein (President)	0415 978 031
Cheryl Ellis (Vice President)	0402 033 652
Robert Butler (Treasurer)	9381 3386
Michelle Dinsdale (Secretary)	0407 197 815

Paul Keogh  
Susie Couper  
Darren Tull

Hard Copy printed by Kwik Kopy  
PERTH

Profiles of committee members can be found on the  
website, at [www.hfwa.org/yourcommittee](http://www.hfwa.org/yourcommittee)

Office Coordinator Ann-Maree Foran  
HFWA Office 2 Delhi Street, West Perth

Phone 9420 7294

Email [office@hfwa.org](mailto:office@hfwa.org)

## PERTH CHILDREN'S HOSPITAL CONTACT DETAILS

Clinic H, Level 1 (Haematology/Oncology Outpatients: Ph: 6456 0170)

Medical Staff: **Dr Tina Carter** Ph: 6456 0170

Nursing Staff: **Natalie Gamble-Williams** and **Stacey Hutchison**

Social Worker: **Emily Johnston** (Three days per week, contact for appointment) Ph: 3456 0413



## FIONA STANLEY HOSPITAL CONTACT DETAILS

Clerk Front Desk: **08 6152 6542**

Medical Staff: **Dr Stephanie P'ng** and **Dr Dominic Pepperell**

Nursing Staff: **Sandra Lochore** and **Lara Olson**

ABDR Data Manager and Clinical Trial Coordinator: **Marina Goruppi**

Entrance to the Cancer Centre is on the outside of the building  
Haemophilia and Haemostasis Centre  
Level 1 Cancer Centre  
Fiona Stanley Hospital  
102-118 Murdoch Drive  
Murdoch WA 6150

Postal Address (address all correspondence as Private and  
Confidential);  
Haemophilia and Haemostasis Centre  
Level 1 Cancer Centre  
Fiona Stanley Hospital  
Locked Bag 100, Palmyra DC WA 6961



Opinions expressed in Contact do not necessarily reflect those of the Foundation. All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. HFWA reserves the right to edit articles as it sees necessary. Material supplied on the internet is for information purposes only and is not to be used for diagnosis or treatment.



Hi Everyone,

## President's Report

I hope everyone is staying Covid, Flu and RSV free - vaccinate where you can.

The World Federation of Haemophilia Congress was held in May in Madrid this year; unfortunately due to the floods in Dubai I arrived late.

It was great to catch up with friends made over the years and have a number of relevant discussions around treatment products, organisational issues, HTC services and other topics.

During the Congress I attended sessions on :

### Gene Therapy

The research is showing generally higher sustained factor levels with Haemophilia B patients than Haemophilia A, but factor levels fluctuate between both. There are a number of trials going on around the world, with some getting better results than others.

At this stage there is an approximately 50% anti body rate to the vector (flu virus that is neutralised to carry the gene therapy) used to administer gene therapy , but there is research into finding other effective vectors to use which will hopefully reduce this percentage.

Research into repeated dosing is being undertaken. All research shows that drinking alcohol does have a negative effect on factor levels.

It was acknowledged that gene therapy has a long way to go and may not become the only treatment used in the future due to some great treatment products in the pipeline.

### Women with Bleeding disorders/vWD

A stream was devoted to women and there are a number of advances being made in diagnosis, setting up treatment plans and recognising women with bleeding disorders in 'difficult' countries.

Early intervention and education is essential. Talk of female arms on clinical trials was discussed for the first time, which was great to see; protocols will need to be developed, but it is essential that this comes to fruition.

There are a number of new products in trial for vWD around the world. Also discussion of using current

factor VIII/IX products containing vWF for the treatment of vWD.

Other topics included **Youth, Rejuvenating Patient Organisations, Developing Countries and the Issues they Face, Ageing** and many more.

HFWA is hosting a Women's Breakfast at Decanter on 13 July (see page 2 for further details) and a Men's Breakfast at Decanter on 4 August (see page 9 for further details).

We hope to have a Sundowner in November (date & venue to be confirmed) and any members over 18 years of age are welcome to attend.

If anyone has any suggestions for activities we are happy to listen please forward any ideas to the HFWA Office.

We continue to attend paediatric clinics at PCH on a regular basis. We hope to see you at an upcoming HFWA event and please get your Memberships in, they are all greatly appreciated.

Regards ,

**Gavin**



Sunny-side up or scrambled?

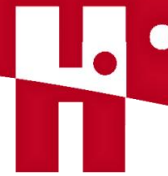
## WWBD JULY BREAKFAST

Please join Cheryl, Susie & Michelle for the Women With Bleeding Disorders event.

Saturday, 13 July 2024  
9.00 am  
Decanter Cafe  
279 Albany Highway  
Victoria Park

Free for current financial members

Kindly respond by the 10th of July to Ann-Maree at [office@hfwa.org](mailto:office@hfwa.org).



## Women with Bleeding disorders Op Shop Event : 20 June 2024

Read on for more tales from the shopping trail.....



As an experienced op-shopper and lover of all things fashion, this was a wonderful day out with other like-minded ladies. Managing to fill my bags three times over with many treasures that have now found a new home rather than ending up in the ever-growing mass of landfill allows me to feel like I'm doing my part in ending the trend of fast fashion. Hearing tips from Lorain on what to look for and knowing where you have gaps in your wardrobe was very helpful. Thank you to everyone involved in making this day happen. I can't wait to experience something like this again, hopefully. *By Brianna Morley*



Three generations of my family had a fabulous day at "How to Op Shop"! The presentation was excellent and we left with several bargains and a greater understanding of the ethical and environmental

advantages of op-shopping. A huge round of applause is due to HFWA and Solaris Cancer Care Op Shop. *By Phoebe and Lisa Box*

## Men's Breakfast: 19 May 2024

A group of HFWA members attended the men's breakfast at the Decanter Cafe in Victoria Park on Sunday May 19th. It has been a fair while since I attended a Sunday men's breakfast. These days my Sunday mornings are busy not sleeping in but watching my kids play sport!

Decanter is a great venue with a tasty breakfast. I'm very appreciative that HFWA covers this, but the food is only a bonus. It is great to catch up with 'old' faces, some I have known since I was a child. As time has passed, I have realised that people with bleeding disorders need support both when they are young, to work out how to manage things; and when they are old as more problems arise and there may be diminishing support around them.

Treatment is good enough that to some extent we can live life independently and 'forget' about haemophilia. However, even with progression in treatment products, treating a person with bleeding disorders still has potential complications and successful outcomes require a strong, knowledgeable, medical system. The breakfast reminds me that as a community we should stay connected as we can help each other, keep each other informed and make sure the state and national foundations remain strong and can continue to provide support.

I understand it is often hard to find the time, but I encourage you all to come along to a men's or women's breakfast sometime in the future. You will hopefully have a good feed, great chat, meet some new people, and learn something. Even if you do not achieve all of that, at least you have supported a foundation that is here to support others. *By Darren Tull*



## World Hepatitis Day 2024



In July 2024 Australian landmarks will be glowing green to raise awareness about eliminating viral hepatitis. World Hepatitis Day is marked internationally on 28 July and is one of the World Health Organization's nine official global public health days. Green is used by the global NOhep movement – the colour of life, vitality and progress.

On World Hepatitis Day the international community comes together to step up efforts to eliminate viral hepatitis, in particular hepatitis B and hepatitis C. In 2024 the national theme is **It's time for action**.

Many people don't know that they have hep C. For example, both men and women could be at risk if they have a bleeding disorder and ever had a blood product before 1993.

Some people have been cured but still need follow-up for their liver health, especially if they have cirrhosis.

Good liver health is a hot topic for everyone in the bleeding disorders community - and in gene therapy good liver health is a requirement. We will be looking at strategies to manage your liver health as part of our World Hepatitis Day activities.

On World Hepatitis Day we are reminded to take action – know your hep C status, have treatment to cure hep C, where possible, and follow up on your liver health after treatment.

By talking to our friends, family or a doctor about testing, treatment, liver health checks and managing liver health we can work towards these goals.

It's also important to be aware that sadly, some people with bleeding disorders and hep C have advanced liver disease caused by long term infection. Close liaison between liver specialists and Haemophilia Treatment Centres is key to care and treatment. Research into management of advanced liver disease is ongoing.

Look out for more information and activities on our website and social media in the week leading up to 28 July.

### FIND OUT MORE

Australian World Hepatitis Day website - [www.worldhepatitisday.org.au](http://www.worldhepatitisday.org.au)

HFA World Hepatitis Day page - [www.haemophilia.org.au/world-hep-day](http://www.haemophilia.org.au/world-hep-day)

*Author: Suzanne O'Callaghan HFA*

**World  
Hepatitis  
Day** 28 July



## Have you done the PROBE survey yet?

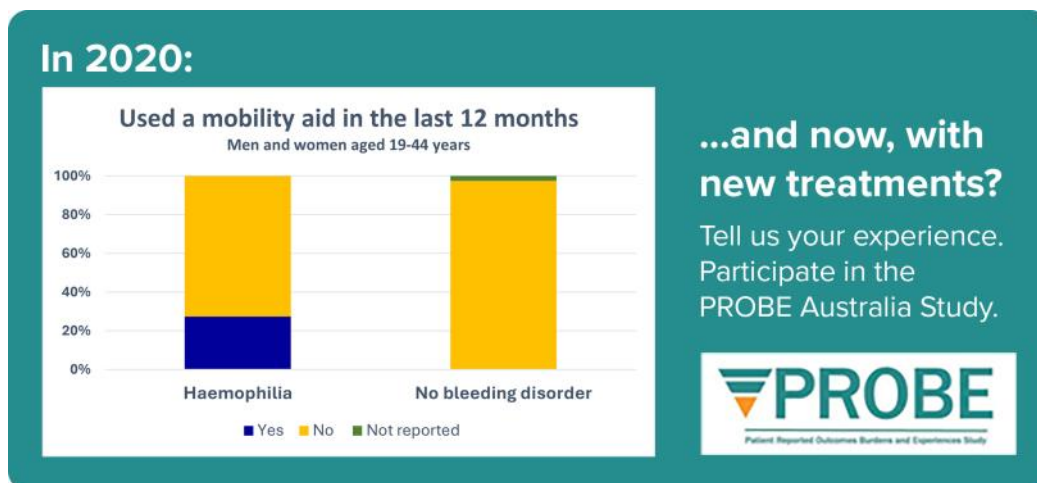
What difference have new treatments made to the experience of haemophilia in Australia?

The **PROBE Australia Study** helps HFA collect the evidence to advocate for new haemophilia treatments. And you can contribute to that evidence.

You can see from our 2020 PROBE study results how many people with haemophilia used a mobility aid like crutches back then – nearly 30% of men and women aged 19-44 years, compared to none of the people without a bleeding disorder in the same age group.

Please consider completing the PROBE survey and tell us what your experience is now.

We currently have about 250 responses. **For strong results we need about 150 more men and women to complete the survey.**



Who can take part?

- ◆ Men and women with haemophilia or who carry the gene
- ◆ AND men and women without a bleeding disorder, like family and friends, health professionals, and other people interested in haemophilia

Participate in the PROBE Australia Study today and contribute to our real-world evidence on haemophilia!

Find out more at [www.haemophilia.org.au/probe-australia-study](http://www.haemophilia.org.au/probe-australia-study).



**HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA INC.**



**Annual General Meeting**

Details for the Annual General Meeting of Haemophilia Foundation WA Inc. is as follows:

Date: Tuesday 17th September 2024  
Time: 7:00 pm start  
Venue: City West Lotteries House — Conference Room  
RSVP: 10 September, Dietary options if required

**Agenda**

1. Opening and Welcome	7. Office Coordinator’s Report
2. Apologies	8. Life Memberships
3. Minutes of 2023 AGM	9. Election of Management Committee - 2024/2025
4. Business Arising	10. General Business
5. President’s Report	11. Close
6. Treasurer’s Report	

**Following the AGM Light refreshments and beverages will be available**

**Nomination for HFWA Committee**

The continued viability and functioning of the HFWA relies on a strong Management Committee. The present committee has a number of long-serving members, and it is critical that we have fresh faces and ideas to steer the Foundation into the future. Contact the office or Gavin if you would like to know more about the Management Committee or how you can assist.

Please tear off and hand to Gavin, Cheryl, Ann-Maree or any of the Management Committee representatives. If you can’t join us for the AGM please send your nomination to the office before 17/09/2024

I wish to nominate for the 2024/2025 Management Committee

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Signature: \_\_\_\_\_



## UK Infected Blood Inquiry and Australia

The UK government Infected Blood Inquiry investigating contaminated blood and blood products released its report on 20 May 2024 after examining the evidence for 7 years. The UK government announced a financial compensation scheme to 'victims of infected blood' the following day. You can read the report at <https://www.infectedbloodinquiry.org.uk/reports/inquiry-report>.

Some of our community members have been asking what this means for Australia.

### THE AUSTRALIAN SITUATION

In Australia the initial situation with collecting blood donations and testing the blood supply was different to the UK. Australia was one of the first countries in the world to introduce hep C testing of the blood supply and had a policy of self-sufficiency in the blood supply (ie, sourcing donations from Australia only). There was an Australian Senate **Inquiry into Hepatitis C and the Blood Supply** in 2004, which investigated and reported on the Australian situation and an Australian government **Inquiry into Hepatitis C in Australia** in 2015.

### WHAT HAS HFA BEEN DOING?

In 2006-9 HFA undertook a hepatitis C needs assessment and described the burden of hepatitis C on our community members in our **Double Whammy** (2007) and **Getting it Right** (2009) reports. The HFA 2020 **Getting Older needs assessment** found that, although the greater majority of surviving people with bleeding disorders who had acquired hepatitis C have now been cured, many have ongoing health, financial and support issues. **HFA has a committee working on a hepatitis C strategy to address this, including the approach to HFA's advocacy, which has been ongoing for more than 20 years now.**

### Eliminating hep C

In the HFA *Double Whammy* report people with bleeding disorders and hep C underlined that their highest priority was a cure. When the new treatments became available in Australia in 2016, we focussed on reaching as many affected people as possible to promote access to treatment and a cure. We are grateful to the HTC's for their tireless efforts to review their patients and encourage them to have hep C treatment and be cured.

### Financial schemes

Although the 2004 Senate Inquiry into Hepatitis C and the Blood Supply recommended case management and financial support for health and community care costs of those who acquired hepatitis C through the blood supply, a formal program was never implemented.

Australian governments contributed to Hepatitis C Virus (HCV) litigation settlement schemes for eligible people who contracted HCV via the blood supply in Australia between 1985 and 1991, prior to the introduction of reliable screening tests for hepatitis C virus. However, eligibility for the scheme involved being able to link the individual's source of infection to a single donor with hepatitis C. HFA believes that nearly all people with bleeding disorders were excluded from eligibility as they had many treatments during this period and usually with clotting factor concentrates manufactured from the pooled plasma from thousands of donations and they could not identify a particular treatment batch or a single donor. Apart from a small ex-gratia payment that was made by the ACT govern-





ment to people with bleeding disorders who acquired hepatitis C through the blood supply, there have been no other government financial recompense schemes for people with bleeding disorders in Australia.

HFA has been active over many years in hep C advocacy. Some key activities are below.

Overview of key HFA activities	
2019-ongoing	HFA consultation with the bleeding disorders community and expert health professionals about ongoing issues with hepatitis C – see HFA <i>Getting Older with a bleeding disorder</i> report (2020). HFA is now working through a strategy to implement the report recommendations (government acknowledgement; health, financial and support issues).
2016-ongoing	HFA campaign to eliminate hep C in the bleeding disorders community and to promote liver health monitoring for those with cirrhosis. Includes: <ul style="list-style-type: none"> <li>• work with Haemophilia Treatment Centres, hepatitis specialists and the community to overcome barriers to treatment and monitoring</li> <li>• education for the community and to GPs to reach those with mild bleeding disorders and those who are disconnected from HTC.</li> </ul>
2014-16	Community consultation on hep C treatment. Submissions to the Australian Government/PBAC on access to new DAA hep C treatments
2015	HFA witness statements and submission to Australian Government <b>Inquiry into Hepatitis C in Australia</b> .
2010-ongoing	Further community consultation about financial issues. Meetings and correspondence with Australian governments on no-fault financial assistance scheme for people with bleeding disorders and hepatitis C and issues relating to out-of-pocket health care costs.
2006-2009	Needs assessment of people with bleeding disorders and hepatitis C and evaluation: <b>Double Whammy</b> and <b>Getting it Right</b> reports
2004	HFA Submission to Senate <b>Inquiry into Hepatitis C and the Blood Supply</b> , including a proposal for financial recompense
2003-4	HFA national campaign for universal access to recombinant clotting factor treatments (synthetic and virus-free)

For a full list of HFA activities and links to the documents, visit the HFA hepatitis C strategy page on our website – <https://tinyurl.com/hfa-hepc-strategy>.

The HFA Getting Older report highlighted that hepatitis C leaves an ongoing legacy for many in our community. We continue to work on a strategy to implement the report recommendations and will advise of any further steps and outcomes.

We are aware that revisiting these issues can be painful for some members of our community. We encourage you to reach out for support if this experience is challenging for you – e.g., to your HTC social worker/psychologist or your preferred counsellor. You may also wish to seek a counsellor through your GP or contact a service like Lifeline (call 13 11 14). **Please contact Gavin Finkelstein for further discussion if required.**

**Information prepared and written by Suzanne O’Callaghan Haemophilia Foundation Australia June 2024**



## Gene Therapy social research study:

Do you have **haemophilia B (factor IX deficiency)**?

Or are you a parent, partner or sibling? Interested in sharing your views about gene therapy?

The University of Sydney is conducting focus groups (small group discussions) and interviews around Australia to find out what people with particular blood disorders and their families think about gene therapy. The findings will help government decision-makers assess whether to fund new gene therapies in Australia.

You will be reimbursed \$160 for your time and your travel costs for a face-to-face interview and \$110 for an online interview.

Click on the link below to express your interest in participating in an interview.

[Uni of Sydney gene therapy research link](#)

## HFWA Membership Renewals 2024/2025

The Aim of the Haemophilia Foundation of Western Australia Inc. is to work towards a better quality of life for people with a bleeding disorder and to provide support for their families by:

- ◆ Providing peer support activities to our community
- ◆ Providing information about bleeding disorders to members and the general public
- ◆ Advocating and liaising with government agencies and hospitals on behalf of the bleeding disorders community
- ◆ Contributing directly to the assistance of members in their education and welfare
- ◆ Supporting research and development of new and improved therapies
- ◆ Encouraging the public to become blood donors to the Australian Red Cross Blood Service

It is that time of the year again ( 30 June) when Your foundation asks you to renew your membership and update any of your details that may have changed from last year. See form Pg 11 and [click for website](#)



Clinic H, Level 1 (Haematology/Oncology Outpatients):

Ph: 6456 0170 If you require further information'

*Say Hi to the HFWA reps that are there.*

July – 7<sup>th</sup>, 16<sup>th</sup> and 30<sup>th</sup>

August – 6<sup>th</sup> and 20<sup>th</sup>

September – 3<sup>rd</sup> and 17<sup>th</sup>

October – 1<sup>st</sup>, 15<sup>th</sup> and 29<sup>th</sup>

November – 5<sup>th</sup> and 19<sup>th</sup>

December – 3<sup>rd</sup> and 17<sup>th</sup>

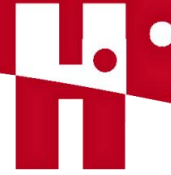


## MEN'S BREAKFAST

JOIN GAVIN ON SUNDAY  
4TH AUGUST AT 8:30 AM.

Decanter Cafe 279 Albany Highway, Victoria Park  
Free for current financial members

RSVP 1ST AUGUST: TO GAVIN OR EMAIL [OFFICE@HFWA.ORG](mailto:OFFICE@HFWA.ORG)



## Arved Wasser Memorial Fund

As a parent of a previous recipient of Arved Wasser funding I want to encourage families to consider applying this year.

We received funding for drum lessons for our child with a bleeding disorder. With a young family, I found balancing the budget challenging. Recreational, extra-curricular expenses fell into the 'discretionary spend' bucket and was often really hard to justify. With the support of HFWA through the Arved Wasser fund, our child was able to participate more broadly in life, try new things and live a full life exploring new experiences.

The end of semester concert was a fabulously memorable experience. I still recall how delightful it was to see them as a performer, as an enthusiastic student and a group participant completely separate to their day to day existence or anything to do with their bleeding disorder.- *Susie Couper*

Arved Wasser Memorial Fund was established to commemorate the enjoyment Arved Wasser gained from attending and competing in an chess tournament, with a little help from the Haemophilia Society of WA (as it was known at the time).

As a 'pay it forward' gesture, the Arved Wasser Memorial Fund was established by the haemophilia Society of WA & his family as recognition of the importance of being involved in joyful & fulfilling activities, and as a way of thanking the HFWA for helping Arved to achieve something that gave him happiness.

Please contact the [office](#) if you would like apply for the [Arved Wasser fund](#) .

This can be added to Apple or Google wallet through the Containers for Change website –

[https://www.containersforchange.com.au/wa/good-causes-directory?keyword=Haemophilia%20Founda-  
tion&category=all&scheme\\_id=wa#findacharityblock](https://www.containersforchange.com.au/wa/good-causes-directory?keyword=Haemophilia%20Foundation&category=all&scheme_id=wa#findacharityblock)

Scan the barcode when you return



Thank you to the generous members who donate their Containers for Change money who visit the Forrestfield and Osborne Park sites !

## Entertainment

Support our fundraising and enjoy 100s of everyday savings!

Entertainment is the easy-to-use App packed with incredible savings of up to 50% off and 2-for-1 offers, so you can save on takeaway, dining, shopping, groceries, gift cards, activities and more! And what's even better, 20% of every membership purchased goes to support Haemophilia Foundation Western Australia Inc.!

[Buy Membership](#)

Bonus Multi City Membership Upgrade\*

12 months

\$70 | SAVE \$50

OR

24 months

\$120 | SAVE \$110



<b>APPLICATION FOR MEMBERSHIP</b>		
	New <input type="checkbox"/>	Renewal <input type="checkbox"/>
	<b>TAX INVOICE</b> ABN 42 961 282 521 GST Registered	
First Name		
Last Name		
Address		
Telephone		
Email		
To reduce the use of paper the HFWA Contact newsletter is delivered electronically. Please tick <input type="checkbox"/> if you would prefer to receive a printed copy via post.		
<b>PRIVACY:</b> HFWA membership automatically entitles you to Haemophilia Foundation Australia (HFA) membership. HFWA respects member's privacy. Your details will NOT be forwarded to other organisations, bodies, or persons without your permission. Please refer to the privacy statement on the HFWA website for details, <a href="http://www.hfwa.org/">http://www.hfwa.org/</a> Please tick <input type="checkbox"/> if you do NOT want your details forwarded to HFA.		
Please indicate:		Date of Birth:
<input type="checkbox"/> Person with bleeding disorder		
<input type="checkbox"/> Grandparents	<input type="checkbox"/> Parent of Child	
<input type="checkbox"/> Nurse	<input type="checkbox"/> Doctor	
<input type="checkbox"/> Other	<input type="checkbox"/> Special Interest	
Please indicate diagnosis details:		
<input type="checkbox"/> Haemophilia A	<input type="checkbox"/> Haemophilia B	
<input type="checkbox"/> von Willebrand Disorder	<input type="checkbox"/> Carrier	
<input type="checkbox"/> Other Factor Deficiency	<input type="checkbox"/> No Bleeding Disorder	
<input type="checkbox"/> Severe	<input type="checkbox"/> Moderate	<input type="checkbox"/> Mild
<input type="checkbox"/> vWD Type		
Please return this membership form via email or to the address below:		
<input type="checkbox"/> Individual <input type="checkbox"/> Family (includes immediate family members) - <b>Membership \$25.00 (GST inclusive)</b>		
Extended family members need to take out their own membership.		
Membership fee can be waived in special circumstances – Please contact the HFWA office on 9420 7294.		
I would like to donate:		
<input type="checkbox"/> \$25 <input type="checkbox"/> \$50 <input type="checkbox"/> \$100    or \$ <i>Donations over \$2.00 are tax deductible</i>		
<input type="checkbox"/> Direct Deposit	Acct Name: The Haemophilia Foundation of WA Inc. BSB: 086 488 Acct No: 035 233 031 Ref: <i>Please include your name e.g. John Smith</i>	