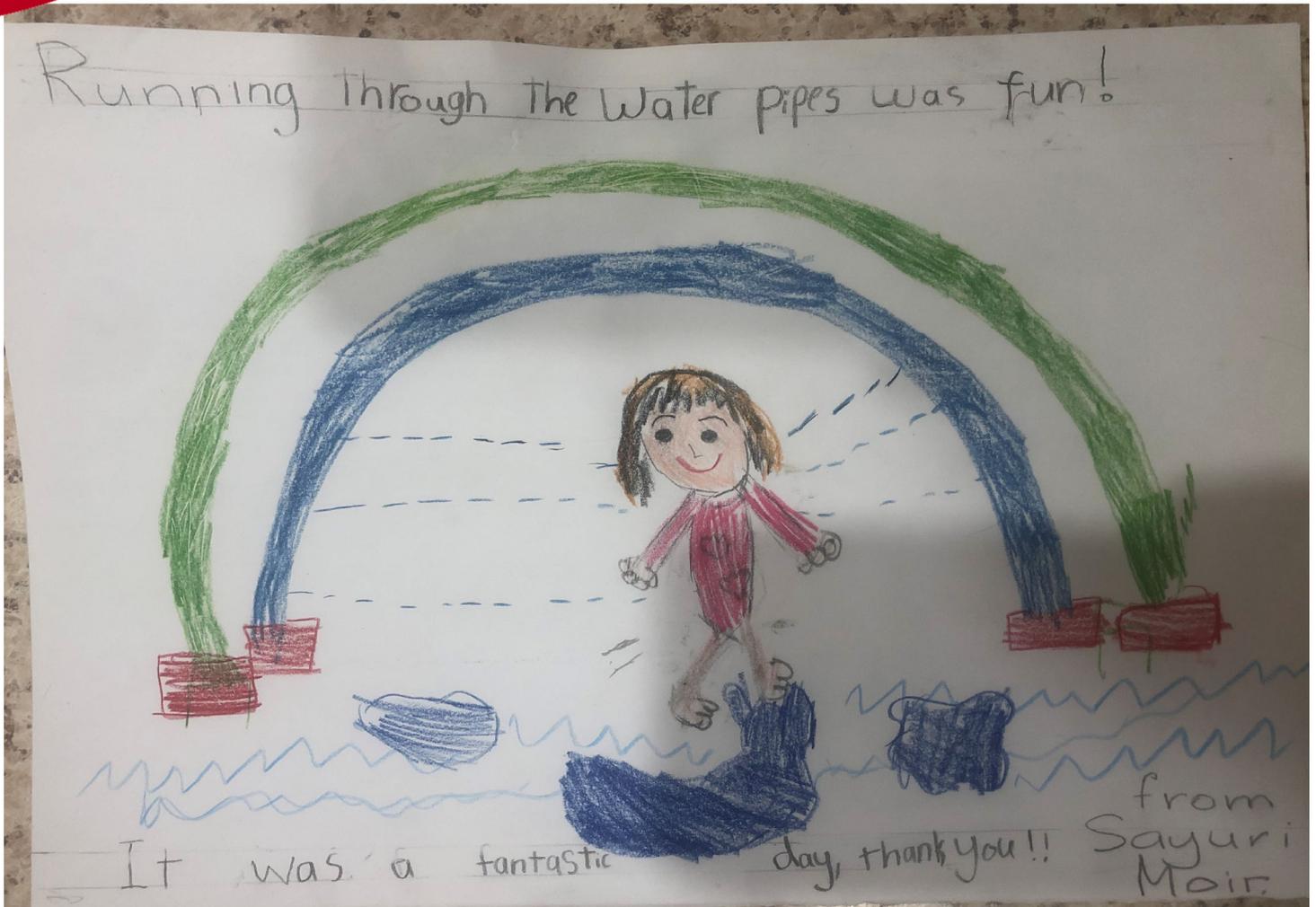
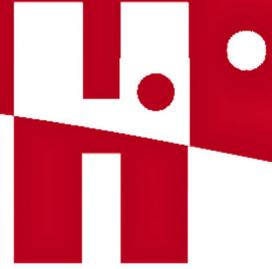


CONTACT

Newsletter of Haemophilia Foundation WA Inc.

February 2023



Cover Picture: Sayuri Moir : HFWA Christmas Party, The Outback Splash Nov 2022

Happy New Year to all of you! HFWA Management Committee extends their gratitude to all members and supporters and it is shaping up to be a positive year back in the Community.

We would like you to all stay safe and well.

Stock images sourced from pixabay.com unless otherwise noted

HAEMOPHILIA FOUNDATION WA INC.

City West Lotteries House, 2 Delhi Street, West Perth WA 6005

P: 08 9420 7294 E: office@hfw.org W: www.hfw.org



CONTENTS

Presidents Report	Page 2
Committee Members Dinner	Page 2
World Congress announcement	Page 2
Responses to recent open letter	Page 3
Christmas Party	Page 4 - 7
Willems Story	Page 8 – 9
Parental Thoughts	Page 10
Resources - Hard copies and links	Page 10
Starting High School	Page 11 - 12
What's on in 2023	Page 13
Posters and events	Page 14
Fundraising	Page 15

YOUR COMMITTEE

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
Eryn Webster

Profiles of committee members can be found on the website, at www.hfwa.org/yourcommittee

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

Phone 9420 7294

Email 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: **Sarah Franz** (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**

Social Worker: **Helena Reynolds** (Mon and Thurs 9:00 am - 1:00 pm, contact for appointment)
Ph: 6152 6527



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



President's Report

Dear Community,

I hope everyone had a restful & enjoyable break over the Christmas & new year period.

We received a number of responses to our plea to the community as to what HFWA (Haemophilia Foundation Western Australia) means to you and how you have benefitted from the activities, advocacy, & peer support provided by HFWA.

The Management Committee has decided to concentrate on targeted activities for the various groups within our community. We are also re-establishing a close two-way relationship with PCH (Perth Children's Hospital) and hope to do the same with FSH (Fiona Stanley Hospital).

What we ask of you, our community, is to please keep your membership up to date (or join - it's only \$25 a year) and support any peer group activities by attending; we welcome any suggestions on what role the HFWA should have and activities we run to engage and bring our community together.

The 21st Australian Conference on Haemophilia, vWD and Rare Bleeding Disorders will be held from 24 to 26 August 2023 in Melbourne, and we would like to see as many people as possible from WA to attend. HFWA will have a limited amount of funding available to support members of the community to attend - more details in the next Contact Newsletter.

Until next time, and hope to catch up with as many of you as possible at one of the HFWA's upcoming events.

Gavin



HFWA Committee Members Dinner 2022

A lovely evening was had by the committee members at the Boston Brewing company in East Vic Park. As a thank you for their service throughout the year and ongoing contributions to the HFWA. Missing that evening were our long servicing retired members Shane Meotti, Dale Spencer. Pictured bottom left: Sharri, Cheryl, Mike & Beryl, Bob & Sheryl, Susie, Lena & Paul, Ann-Maree, Darren and Aaron. Unable to attend Gavin Finkelstein, Michelle Dinsdale & Evyn Webster

National Conference 2023

The first and very exciting thing to tell you is the 21st Conference on Haemophilia, VWD and Rare Bleeding Disorders. It will be held 24 -26 August, 2023 at Pullman on the Park in Melbourne. Registrations will open in February and confirmation of the cost for registrations and accommodation is currently underway. Check the HFA website for updates.



Responses to Our recent letter in the November newsletter

Reproduced with permission from authors

My name is Sharri Brodie and my son Willem has severe Haemophilia A. I also now know I have mild haemophilia and mild von willebrand disease..

He was diagnosed at 5 days old and I will never forget the feelings of fear, guilt, confusion, anger and sadness that I felt that day.

HFWA and all of the people and its resources supported us immediately and the amount of care and kindness shown to Aaron and I was overwhelming. We no longer felt so isolated and knew that any help or reassurance we needed was only a phone call away.

I chose to be an active HFWA member and have always felt the need to do what I could to repay the gratitude that I still hold today toward the foundation.

I have always felt that it is very intrinsic in a person to want to give something back to the community - whether that is by volunteering time, resources or using your skills to help others.

I am very proud of my own family too for always stepping up when required. Particularly my own Mother - she has contributed enormously and never wanted any recognition - she did it for our family and other families like ours.

My husband and children have also been believers in "paying it forward". They are grown men now but are still happy to sell sausages, move stuff, mentor younger kids and do whatever is needed.

I know treatment is fantastic now and perhaps family don't see the need to be involved with our foundation. I suppose that is a good thing and I do appreciate that times change and we all need to adjust to that.

I am not sure how our community will respond to the plea for feedback. I just wanted to say thank you to each and every person that I have met along the way - many of you I consider close friends. I will always be grateful for the support and care that you have given to my family and I and as always, I am here if you need me.

Sharri

Good afternoon

We would like to comment on the possible closure of HFWA.

There is an important advocacy role that HFWA has always provided to the members of the haemophilia community in Western Australia, to assist in making new treatment products available, and it would be a great pity if HFWA was to close. Unfortunately we are some of the members who have not made a contribution to the running of HFWA, distance from Perth being the main influencing factor, however we appreciate the role that HFWA has played in bringing young people in particular together so that they do not feel alone in dealing with a not-well-known medical condition.

We hope that there is enough support from the haemophilia community to warrant 'keeping the doors open'.

Kind regards

Ray & Meryl Oversby



Family Christmas Party : 27 November

HFWA held the annual Christmas Party at Outback Splash in Bullsbrook. It was a mild November day which made for less flies and more fun. Over the next few pages are some of the photos of the families that were able to join in on the fun and festivities. The man in the Jolly red suit was able to visit us and had many great early Christmas



2021. This is part of an ongoing plan to alternate between hosting events north and south of the river. Let the office know if you have any suggestions.



presents for the kids. He was enjoyed by all and even got a serious grilling from the Moir girls.

The cover page is a beautiful depiction of the day as enjoyed by Sayuri Moir

Once again our members and their families had a wonderful time and I would like to thank those of you that were able to join us on this very successful day. Plans will be underway for the 2023 Christmas party—we are hoping to hold it at Adventure World as we did in











Willems Story: Haemophilia – the spice of life

Credit to the HFA newsletter for the article. For those of you who have not read the interview with HFWA's own Willem Brodie, below is an excerpt.

Willem spoke to HFA about working, exercising and being out and about in these days with new treatments.

Tell us about you and your bleeding disorder

At the moment I'm working in headphones diagnostics and repairs. I test headphones with software for any issues or errors, clean them up and send them back to return to the customer. It's great – my own office and chair!

Over the years I have had a few different treatments. Currently I'm on emicizumab (Hemlibra®), which is more time-efficient for me. I only have to infuse once a week, rather than every second day with my previous treatment, and it's very useful to be able to wake up and get my infusion done in 5

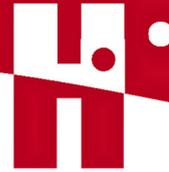


minutes. I have very early shift starts at work and have to be in town by 7.30am, so to be able to do my treatment so quickly and get straight into town is amazing.

My new treatment is more consistent for me too. I have had no bleeds at all – no sensations of a bleed, no bruising that takes a while to go away. I think others have had some issues, but I haven't. With my earlier treatment, it would depend on the timing of the treatment and whether I was being physical and I would still have some spontaneous bleeds. But now I can go through the week confidently like anybody else and not think should I do this because of the worry about injuries or bleeds.

Photos supplied by Willem and reproduced with permission





Willems Story: Haemophilia – the spice of life cont.

What else are you up to?

I really enjoy going to the gym and catching up with my mates there. These days I can go to the gym and be full on without having to worry about after-effects with bleeds. I love gym, but with my previous treatment, it used to be quite daunting for me. With any stress or pushing myself too hard, it always used to end up with a bleed, but now if I push myself, it's more



about being careful of muscle strain.

I've been getting around and seeing more of the city lately and trying out some new things. I hang out with my friends at the pub or see what else there is to do, maybe see a movie. At one stage I had an interest in axe throwing. I used to catch up with people after work to do it now and then. It was great fun – just a bigger version of darts and makes you feel more Viking and Nordic!

What have you learned about managing haemophilia to enjoy socializing and recreational activities?

With my current treatment, I just have to maintain my treatment as usual. When I was on my previous treatment, I learned to organise dates and times with my treatments, just to stay safe. If I had quite physical things like going into town or paintballing, I would aim to treat the same day or the day before. That meant I could get the maximum enjoyment out of the day instead of having repercussions pop up later.

It's good to let your friends and family know about your situation and make sure they understand it. And when they have an idea for an activity, to talk to them about how to plan it so you get to participate and there is a care for your wellbeing, for example, in case of emergencies.

When I think about it, haemophilia has really had an impact on who I am and how I deal with life. In my case, it has made me a more calm and collected person. I don't have an interest in violence and I don't react by being rough or angry. I think because growing up with haemophilia there are limitations with the physical, it makes you less likely to become physical. It's a good life lesson.

READ MORE :Check out the personal stories from other young people with bleeding disorders on:

Factored In, the HFA youth website - www.factoredin.org.au

The **HFA YouTube channel** - <https://tinyurl.com/HFAYouTube>



Parental Thoughts to Share

Reproduced with permission from Author:

"I always love reading all the articles, and one that stood out for us was the one about prepping for haemophiliac children starting school and how to prep the teachers.

I wish there had been similar articles when we first started Finnick at day care when he was 10 months! We had no clue how to deal with a haemophiliac baby that was starting to walk and constantly falling, we got him a soft helmet far too late which would have helped manage his falls and avoided a lot of bruises to the head during his stay at day care and under the supervision of someone else other to a parent.

Another thing we tried to do on our own, was to educate the day care carers about the bleeding disorder and really make them understand what it involved. Like the article states, it is so important to educate the school/ daycare. When you gave me all the info packages, there were 2 posters amongst them what to do in the event of a bleed, I took those straight to the daycare centre, as they were a great visual!

We changed Finnick from one day care to a different one where he is now and they are amazing at watching him closely and trying to avoid injuries or at least very onboard with communication whenever he bumps himself. They were also very diligent in keeping his helmet on when he first learned to walk."

Ally

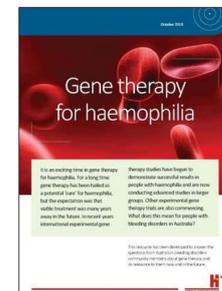
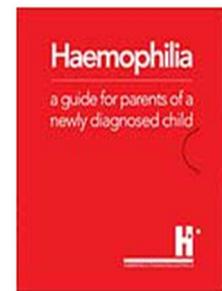
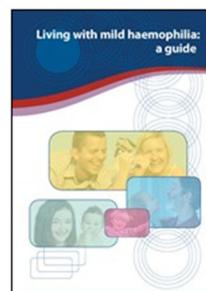
Bleeding Disorders resources :

We have some resources in the office for families, teens, young girls, travel, sport, starting school, Hepatitis C, treatments... Please contact the office if you would like some posted out or if you would like to pop in and take a look.

There are also many resources available on the HFWA and HFA's websites, click on the links below to take a look -

<https://www.hfwa.org/publications/information-resources>

<https://www.haemophilia.org.au/publications>





Starting High School

Starting high school is such an exciting time for young people and their families - but it may be filled with a bit of apprehension too! The school is likely to feel and be a lot bigger than their primary school and it can be easy to feel a bit lost and nervous when they begin.

Orientation days are a fantastic way to feel more comfortable in the environment. Another way to ease transition is for parents and guardians to chat openly and honestly about what high school might look like and what ways you can troubleshoot any issues.

Tips and tricks for high school

- Tell your HTC your young person is transitioning to high school. The sooner they know, the more time they have to help with transition.
- Find your contact! Help your young person connect and feel comfortable with their year advisor, First Aid Officers and/ or Wellbeing Officer. This is the staff member who will be your and your young person's contact for school issues, further support and firsthand knowledge of bleeding disorders.
- Some young people may need access to the bathroom during school time due to heavy periods. Discuss this with the school and check if your HTC may need to provide support or advice.
- Make sure your young person keeps sanitary items readily available for school in case of flooding. A key contact at school is very useful for this issue.
- Make sure your Emergency plan is up to date and completed by your HTC as required.
- Your HTC will offer school education sessions, either pre-recorded, virtually or in person.
- Plan ahead - work with the school and your young person regarding camps, excursions and sporting events so everyone is prepared.
- Talk to your young person about wearing a MedicAlert® ID bracelet or necklace or something similar. Make sure the emergency screen on their mobile says they have a bleeding disorder and that they carry their ABDR patient card in their wallet or have a photo of their ABDR card on their phone.



Tell us what you're proud of....

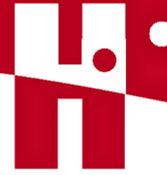
"guess what my child has accomplished"

"look at what we can do now"

"look what team we made"

We love to receive your emails, so contact me at the HFWA office with a few lines or a lot of lines and a picture so we can share in an upcoming newsletter.

office@hfw.org



Starting High School (continued)

ENCOURAGING INDEPENDENCE

High school is a time where young people start to move away from their parents and caregivers and start to exert independence. Sometimes this is a difficult time for the parents/caregivers, especially in the context of a bleeding disorder. While some young people crave freedom and independence, others may need that extra push to become confident and self-motivated. Wherever your young person sits on this spectrum, there are ways everyone can help young people thrive. Skills you can help your young person practice are:

- **Being independent at home** - learning to cook, being responsible for cleaning areas of the home, doing their own laundry
- **Managing their time** - becoming responsible for their own work and study and learning how to create, maintain and stick to a timetable is very helpful for high school life
- **Increasing confidence** - learning to deal with new situations, meeting new people
- **Being responsible** - looking out for their friends and themselves
- **Taking responsibility for their bleeding disorder** - making their own appointments, attending part or all of their clinic appointments by themselves
- **Having a sound knowledge of their bleeding disorder** and what this means to them
- **Being responsible for their own treatment**, as applicable.

Other ways to encourage independence are to create clear boundaries which may evolve as your young person gets older. These include:

- **Going out with friends** - where are they going and how late can they be. They need a person in their group who knows about their bleeding disorder. Discuss who it will be and how they will help in case of an incident/accident
- **Contacting when they are out** - when and how they should check in
- **Using social media devices** - what platforms are okay and any device-free times.

IT IS OKAY TO LET GO!

As a parent or guardian you want your young person to grow into a confident, capable, knowledgeable adult. Your HTC wants this too! When you begin to progressively let go and allow your young person to become more independent with life with a bleeding disorder, you learn to trust them and they learn to trust themselves.

High school will be a bit of trial and error on both sides of you and your young person. With a bit of trial and error and help from your HTC, your young person will learn to trust themselves and the decisions they will make both about their lives and their bleeding disorder.

High school is an amazing time of growth for a young person. With the steady guidance of parents, caregivers with the support of the HTC, they can learn, grow and go on to great things.

(Source: HFA website, [Starting school with a bleeding disorder](#) *National Haemophilia Journal*, No 220 December 2022)





WHAT'S ON IN 2023.....

Women's High Tea - 11 February 2023

Men's Breakfast - 12 February 2023

Rare Diseases Day - 28 February 2023

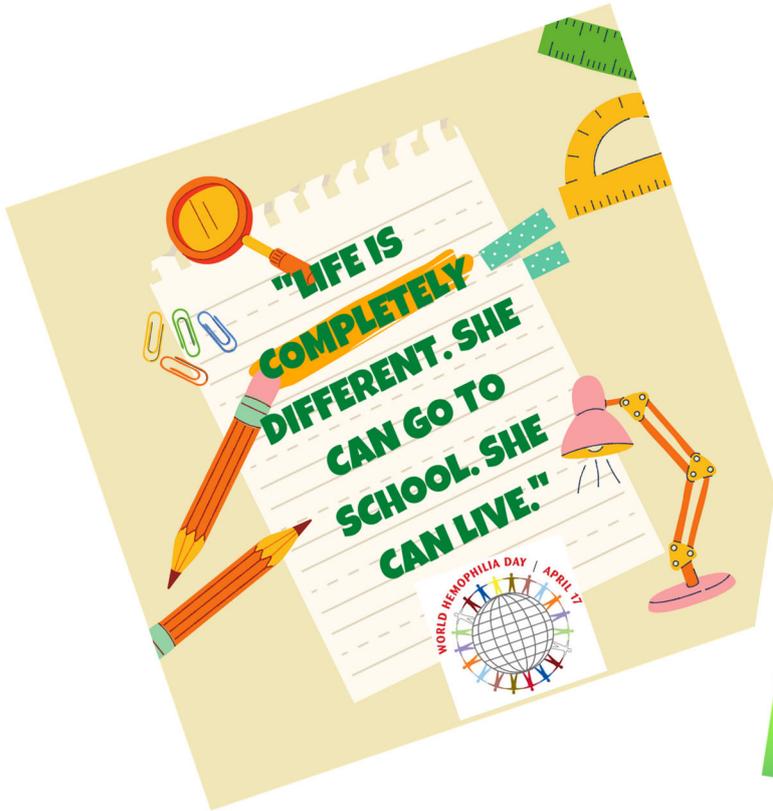
Family BBQ - 12 March 2023

World Haemophilia Day - 17 April 2023

WFH 2023 World Congress Buenos Aires - 10 - 12 May 2023

Bleeding Disorders Awareness Month - Oct 2023





CONTACT

February 2023

Page 15



HFWA are selling quality shopping bags to support our state programs.

To order your bags and arrange collection

email: office@hfwa.org.au



Jute Large Shopping Bag

42cm W x 33cm H



Red Shopping Bag

33cm W x 35cm H



Email your order for the shopping bags with your name, address and phone number and we will advise when your order can be collected - or we will dispatch your order promptly by mail (postage can be arranged at extra cost)

For fast payment, secure

<https://checkout.square.site/merchant/06461WB19EDA8/checkout/R74ZARTGOWNVOO6YVONMBHMX>

and secure follow the Square credit

card payment link below or simply scan the QR code to go straight to the Square checkout

or deposit the total of your order with your Surname as your reference to:

Acct Name: **The Haemophilia Foundation of WA Inc.** BSB: **086 488** Acct No: **03 523 3031**



Scheme ID

C10338968

WHAT CONTAINERS ARE ACCEPTED?

Most aluminium, glass, plastic, steel, and liquid paperboard drink containers that are 150ml to 3L can be returned to Containers for Change.

Just check for the 10¢ mark.

Thank you very much to those who have donated their refunds to HFWA!

