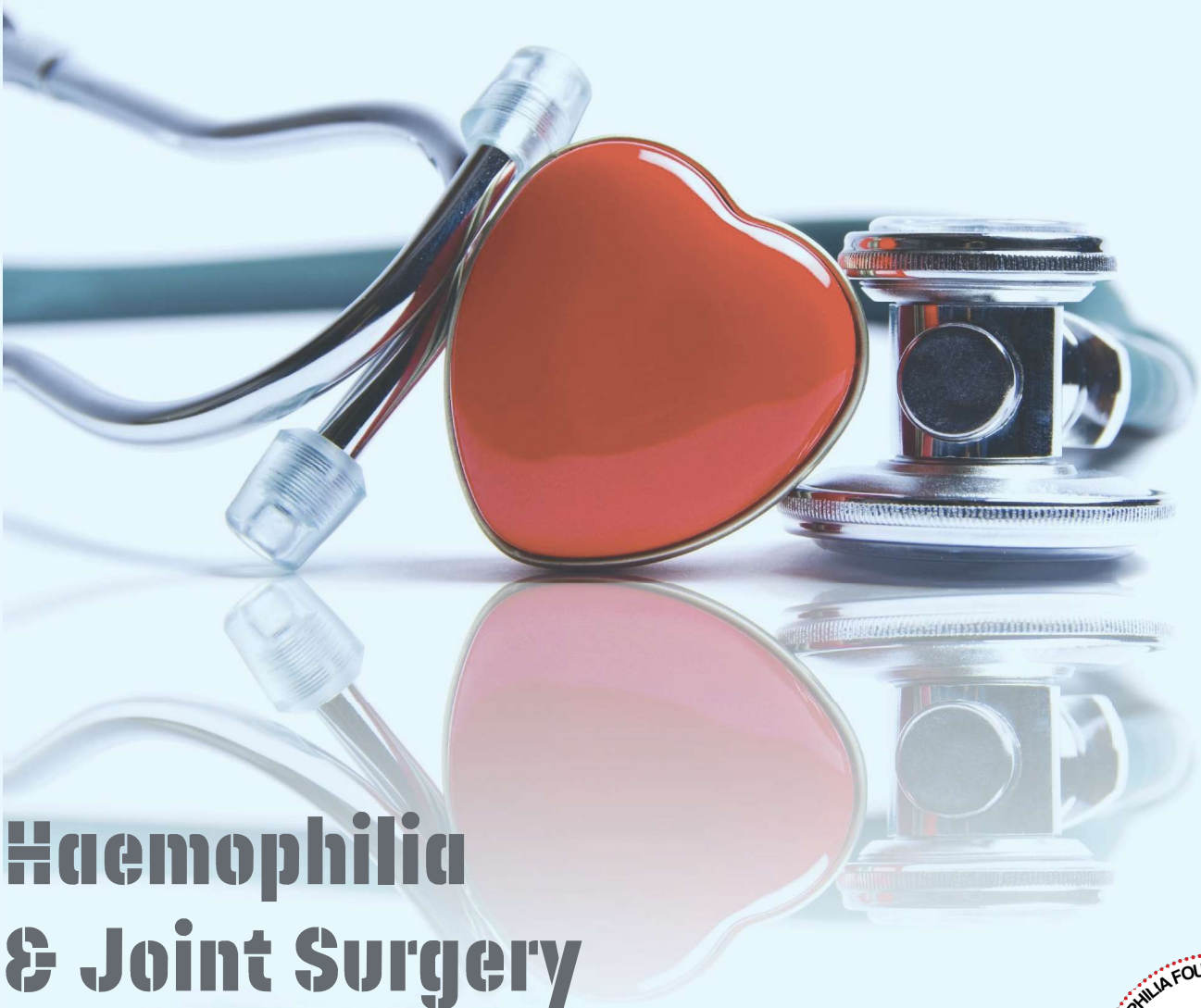


THE MISSING FACTOR

VON WILLEBRAND DISEASE

*Debunking Myths
& a CALL TO ACTION*



**Haemophilia
& Joint Surgery**

connect • support • empower



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Ask Us - Q & A's from the Alfred Team

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HFV is committed to Child Safety.

Our Child Safety Statement is available for review on our website www.hfv.org.au

The Missing Factor is the official publication of the Haemophilia Foundation Victoria (HFV) with four issues annually.

Opinions expressed in The Missing Factor do not necessarily reflect those of the foundation, HFA or the Haemophilia Treatment Centres. The content of this publication is provided for information purposes only. All information is provided in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. No claim is made as to the accuracy or currency of the content at any time. HFV do not accept any liability to any person for the information which is provided.

HFV is funded through the Department of Health and Human Services under Blood Borne Virus Sector - due to the historical impact of contaminated blood products on the haemophilia community. HFV supports our diverse community and our magazine reflect topics that impact our community including Bleeding Disorders, BBVs, Mental Health and positive health promotion.

Editor: Julia Broadbent



Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.



PRESIDENT'S REPORT

It is that time of the year that we all reflect on where we have been, where we are going and what can we take forward into the new year. All of us at HFV have taken some time to thank our stakeholders and reflect on a year well done. However, saying thank you can become repetitive and lose its impact with time even though it is very sincere and genuine by us all.

So this year I will share my analogy to reflect on a year well done. Think of community support agencies as a series of trains. Each have a journey, each have special passengers and destinations to reach, each are coming and going depending on where people need to be at that time in their life journey.

HFV is *your* train:

- **Our Members** are our passengers. Precious cargo that we help to get from one destination to another. Getting on and off depending on what they need, we encourage a myki card through membership but happy for some to take the journey without a ticket in hope they will buy one when they need it.

- Trains need tracks. **HFA** provide some of those tracks. Make sure the broader network doesn't crash into each other, allow a space for growth, make sure the passengers that ride the trains have the info they need to buy tickets and support HFV with the service provided once on board. HFV have diverse travellers and HFA assist in staying ahead of their needs and promoting to the broader community the need for the HFV train. A very special thanks for all the amazing work in creating such valuable resources

and make sure you check out the new Community Camp video and Female Factor resource.

- Passengers don't just need a train. They need destinations that will support them. Stations in life to address their specific need and get them ready to get on different trains through their life. We are blessed to have two Rolls Royce quality stations in Victoria – **RCH and The Alfred**. Many thanks to both for supporting our passengers above and beyond their station, attending the community camp and the time and energy they spend in providing support across the years. Another successful teacher seminar again this year at RCH and to the Alfred many thanks for your extra assistance to reach some of our rural passengers.

Our stations keep everyone on board when they go to sleep, connect us especially to the rural passengers or new ones that haven't been brave enough to consider a train trip let alone buy a ticket. Support and encouragement to our families to reassure them it is all going to be OK and they will reach all their destinations along the way.

- Train trips get boring if there are no new destinations along the way. **Purple Soup** help to build fun and engaging parts of the train trip through camps and activities but also go above and beyond with individual support needed for our passengers at times along their trip.

- A good train network needs planning for the future. They need to know what has worked and what hasn't and need a wisdom that comes from the experience of

those travellers before us. For HFV this comes from our **Patron, Dr Alison Street**. Thank you Alison for your time and knowledge in supporting our train trip and our planning for the rough journeys ahead.



TRAINS NEED FUEL TO RUN

- through financial grants provided by HFA
- through the hard work of many in fundraising with a special mention to the Field family, the Grant family and all on our fundraising sub-committee.
- through the generous support from DHHS who show that they value our train by their ongoing support and we look forward to continuing our journey together.

TRAINS NEED DRIVERS

Often as President I get to wear the driver cap but leadership is shared across the committee. Many thanks to all committee that step up many times over. They offer the engineering behind the train with input to strategic thinking required to plan for journeys but also do the hands on tasks when needed. Regional visits are a big commitment by HFV and not possible without the committee prepared to lead and follow.

We all contribute to the train journey and the platform experience for our commuters, but no one has the train more at heart than **the staff** who:

- + encourage everyone to buy a myki and to use it as needed
- + make sure the train is living up to timetable expectations with DHHS and committee on track
- + make sure our wonderful pro-

grams and timetables along with journey experiences and challenges are shared through our magazine

+ thank you for their most welcoming approach to all at stations and those on the train journeys. Help on board, making sure everyone is comfortable, has an appropriate seat in the right carriage with fellow travellers to share their journey and story and making sure our passengers are heard, understood and supported.

This is not an ad for Met rail but an analogy to show that living with a bleeding disorder is a life journey, lots of changes of platforms and with support our passengers have choices to travel anywhere that any network may take them.

Connect support and empower

HFV can connect the trains, support members on their journey with the tickets they need and the connecting trains where possible

and empower them to say 'hey this journey is not the one I wanted' or at times just sit back and enjoy the ride.

Always remember to tap on at the start of your journey. We need our passengers to have paid for their 'myki card' to support our train. HFV provide a ride that gives the space to enjoy our ride but we are always planning and fixing the little things that go wrong from time to time. Just like the rail system it is a competitive market for contracts and we need to make sure our train stays funded, shiny and loved by all the stakeholders. We can't do that without the support of everyone at the stations, our extended HFV family beyond, the broader network and most importantly you as our precious passengers.

So jump on board, renew your myki for the journeys ahead and lets work together for future journeys. I am sure HFV can continue to grow with new carriages

for new passengers, clean and comfortable seats for our older commuters and not only stay on existing tracks but build our own tracks to take people with bleeding disorders to new and exciting frontiers.

Thank you for your support, take time to refresh your own engines with your family and loved ones and hope you get to enjoy some holiday time healthy and relaxed without challenges. The HFV train will be revving up in 2019 so get ready for the ride. It will be exciting, inclusive and safe so make sure you are a part of it.

All aboard in February 2019 and book your ticket for the Community Camp in April now as it is going to be a hoot. Safe and happy holidays and see you in 2019.

Leonie Demos
HFV President

NEVER BEEN TO A HFV CAMP?

Family and community Camps

Watch later Share

check out this video and see what it's all about...

<https://youtu.be/oiFj9aZMWLk>

MORE VIDEOS

2:50 / 2:57

YouTube

Still not convinced? ...just come for a day! Details page 15

NEW RESOURCE FOR YOUNG WOMEN



HFV are excited to be able to share HFA's new innovative resource for young women and teenage girls.

It has been a huge undertaking on behalf of HFA but highlights the evolving world of bleeding disorders. This resource aims to explain bleeding disorders in detail in a way that is easy to understand for women, your family, partner and friends.

FEMALE FACTORS: INFORMATION FOR YOUNG WOMEN WITH BLEEDING DISORDERS

This was developed to answer the questions of young Australian women about how bleeding disorders affect females – but in a magazine style that is fresh and engaging. There are personal stories, quotes and tips.

HFA worked with haemophilia and gynaecology experts, who put together easy-to-read information for young women.

The booklet has explanations about heavy periods and other bleeding symptoms in females, covering all bleeding disorders. It answers FAQs - such as what's 'normal' and what's not normal, or why girls with haemophilia have different bleeding patterns to their father or brothers - and gives frank but reassuring answers to some of the questions young women worry about.

HOW TO ACCESS IT

Female Factors is available in multiple formats

- A print copy has been enclosed in this edition of The Missing Factor
- On the HFA website www.haemophilia.org.au under PUBLICATIONS
- On Factored In www.factoredin.org.au under INFO > GIRLS
- You can read the entire booklet online as a magazine in ISSUU, download it, or download specific sections

Many people were involved in developing Female Factors. Both young women and their parents and health professional experts suggested what topics to cover, reviewed it thoroughly and wrote new content or gave personal experience to answer questions.

HAEMOPHILIA & JOINT SURGERY

A discussion regarding joint surgery is commonly had between people with haemophilia and their medical team. It is well established that recurrent bleeds into joints can lead to arthritis. The exact mechanism of why the damage occurs is still being researched; however it has been established that the exposure of joint cartilage (which covers the ends of bones that form a joint) to various chemicals present in blood (ie; during a joint bleed) causes degradation of the cartilage. Without the cartilage between the bones to buffer impact, the bones may develop osteophytes (excess bony growth), or cysts (areas where bone has been lost). If bleeds are managed well; early factor, rest of the joint during the active bleed (and until pain-free movement has been restored), and rehabilitation of the joint to ensure optimal biomechanics and muscle action has been restored; then the likelihood of the development of arthritis can be minimised. The presence of synovitis (inflammation of the joint lining) and decreased joint function can increase the potential to develop arthritis.

It should be noted that some cartilage thinning and changes are a normal part of aging (like grey hair) and what can be seen on an x-ray has been demonstrated not to have good correlation with the amount of pain or dysfunction someone may experience. This article is not intended to predict everyone with haemophilia will need a joint replacement. Rather it seeks to answer some of the frequently asked questions.



reported success rate. This is because these joints are the most common sites of osteoarthritis in the general population and surgeons have the most experience and development with these joints. In people with bleeding disorders the elbow and the ankle are two common sites of arthritis.

First line management for arthritis has been extensively researched and clinical guidelines recommend weight management and exercise (both general and specific- as prescribed by physiotherapists). Analgesia that is suggested by and prescribed by a doctor can also aid symptoms. Of note - Non-Steroidal Anti-Inflammatory medications (NSAIDs – for example Neurofen, Ibuprofen, Voltarin and other medications) often prescribed in arthritis, have been found to increase bleeding. These should never be used unless in specific consultation with your haematologist or HTC.

Joint replacements are the last-line solution to joint management. Many questions have arisen regarding this and this information seeks to try and answer some of these.

What is a joint replacement?

A joint replacement is an operation where the two ends of a bone are excised (cut away) and a synthetic material replaces the bone that was present.

Which joints can be replaced?

Hip and knee joint replacements are common and have a good

Currently there are surgeons who perform ankle replacements but this is a relatively new procedure. We do not have the long term data for this operation and there have been reports in some of the available literature of higher rates of infection and operation failure. At this stage the longer term data does not show superior outcomes for one over the other, however given the increased risk associated with ankle arthroplasty (infection / hardware failure) fusion remains the recommended approach. With increased time and studies this may change. We do consider joint fusion in the ankle; this is where the joint is fixed in one position, which usually gives complete relief of pain but may limit movement.

Elbow replacement is not common but can be performed if necessary. Elbow replacement can give relief from pain but patients are limited to lifting loads of under 5kg, and stability can be an issue afterward. Other joints, for example the shoulder can (rarely) be replaced, which can be an effective procedure for alleviation of pain but typically results in diminished overhead and behind back function.



What is the best time for a joint replacement?

Joint replacements can technically be performed at any age, however there are many considerations.

The operation is typically a significant procedure requiring a prolonged period of time under an anaesthetic. A person needs to be medically well enough to tolerate a long anaesthetic; for example someone with heart or lung issues may experience difficulties with this. The life of a prosthesis (the term for the new joint that will be inserted) is quoted differently in various literature, however currently seems to be around 15 years. This will obviously depend on individual circumstances and could be much longer or much shorter. As an example, an older or less active person is less likely to put strain on the prosthesis than a younger, more active person who engages in repetitive higher loading or twisting activity; this can decrease the length of time it can be comfortably tolerated due to prosthetic loosening.

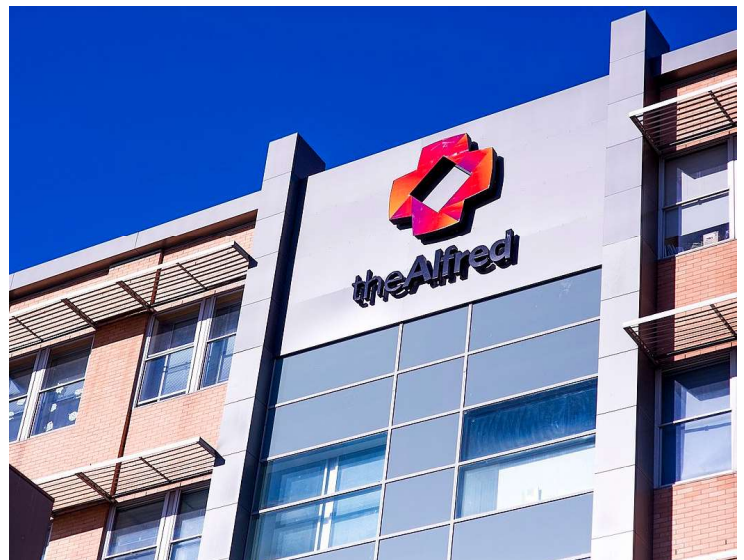
At present it is usually possible to do revision surgery (a procedure involving replacing part or all of the existing joint replacement) for total joint replacements, but this is a much larger operation and will depend on the bone-stock (how much bone and the quality of the bone)

available at the operative site. One revision is usually possible, however it is not usually possible to do multiple revisions because of bone stock. For this reason if we consider a joint replacement on a 70 year old; in 15 or so years he may benefit from a revision, in another 15 years it is reasonable to speculate that the joint may not be the overriding issue at 100 years of age. Considering the same timeline for a 40 year old; in 15 years and then another 15 years, this may have significant implications for life and activity if at 70 years of age we are unable to control the potential pain and loosening of an old prosthesis. On the other hand, it is reasonable for people to want to live in comfort rather than pain and to be able to perform functionally in the way that they want to. If a person, regardless of age, is unable to perform their usual work and activities due to poorly controlled or escalating analgesic (pain relief) requirements, then this would be a

consideration to discuss the possibility of having a joint replacement.

Where is the best place to have a joint replacement?

It is generally recommended that you have a joint replacement in a hospital that has a haemophilia centre. This means that you will have best access to specialists who understand haemophilia, can support you factor levels (or other blood levels) and who are aware of what to do if something does go wrong! Every hospital is different and has different policies so it is worth talking to your HTC to discuss this. Typically the hospital stay for joint replacements may be 3-5 days, however if factor cover is necessary (and with haemophilia (mild, moderate or severe) or vWD it will be) it can be 7-14 days in hospital to ensure that bleeding does not occur.



In the state of Victoria it is advised that all joint replacements are performed at the Alfred Hospital. Private hospitals will not have the same expertise in managing people with bleeding disorders. We do try and recognise that private hospitals may have shorter waitlists but for safety we recommend haemophilia expertise over timing. If it is thought that a joint replacement is warranted in a patient with a bleed-

ing disorder the HTC and rheumatology team can sometime liaise with the orthopaedic department regarding timing. We recommend you contact your HTC if you have joint issues and can be directed to the physiotherapy, rheumatology and haematology teams accordingly, with onward referral to the orthopaedics if needed. This usually works out quicker than being directly referred to the orthopaedic department by your GP.

Prevention is better than cure!
Of course prevention is better than cure. All bleeds should be adequately treated in a timely manner with the correct dose of factor replacement. The less time the exposure of a joint surface to blood the better. There is also some emerging evidence that weight-bearing on a joint that is bleeding is more damaging to the cartilage than not putting weight on it. (That's why your physios nag you to use crutches and completely rest the joint!) So having enough time off the joint that is bleeding is vital. As a general rule of thumb, you should have FULL, PAIN-FREE range of movement before you weight bear on a joint that has been bleeding; every bleed is different though so please contact your HTC physiotherapist for individual guidance.



Similarly there is a mountain of evidence of what the best management of osteoarthritis comprises. In the last 15 years many different treatments have been compared in rigorous scientific studies and it has been found that weight management and exercise are two

interventions that can optimise management of pain and symptoms. Building muscles to support a painful joint and to regain normal control, muscle activity and walking has been shown to be extremely effective in managing symptoms. Trials involving people on a joint replacement waiting list who un-



dertook an exercise program found that: about 1/3 will go on to have a joint replacement, 1/3 will delay a joint replacement a few years and 1/3 will not need to have a joint replacement at all.

Before and after a joint replacement

If a joint replacement is ultimately performed, it is IMPERATIVE that you complete your rehabilitation. If you have the operation without the full rehabilitation you are unlikely to get the full benefit of the joint replacement, as you may be lacking muscle power, joint control and range of movement. This can usually be performed in the hospital or at a local (public or private) physiotherapist. Your hospital physiotherapist may refer you to a local physiotherapist, however if you note increased pain, heat or loss of range of movement occurs you should immediately contact your HTC. You may need some prophylactic cover (if you do not usually have it) for physiotherapy during your rehabilitation. Talk to your local HTC for information regarding this.

There is also some research to show that an exercise program prior to a joint replacement can get you 'operation ready' and improve your outcome after the operation, as well as speed up the recovery process. Again, liaise with your physiotherapist at the HTC and this may be able to be accessed locally.

Caveat - this article is general advice and information and does not take into account specific circumstances. Please discuss with your personal health care team at the HTC for specific advice.

**Abi Polus
Senior Clinical
Physiotherapist -
Haemophilia, Alfred Health**

Info arthritis Australia ++
Studies++

STRENGTHENING COMMUNITY ONE FAMILY AT A TIME



Gather My Crew is an online help roster that uses technology to make it easy to ask for and coordinate the right kind of help from friends and family when going through a tough time.

Our free online help roster links people in need to their own network of ‘helpers’ in an easy and coordinated way.

Gather My Crew can be set up on a computer, tablet or smartphone and used to coordinate helpers to assist with:

- Jobs around the home
- Medical appointments
- Daily chores
- Young children
- Transport
- Arranging an outing

“A friend set up Gather My Crew for my family when I experienced health complications and extended hospitals stays meant my husband needed support in caring for our family. We have no immediate family living nearby, so the support we received was invaluable. We were thankful for the different areas that help was

provided – from transporting children to and from school, to meal support and even visiting rosters! It was helpful to have a central location to direct people to who offered help, and to have all the information in the one location. Accepting help is not always easy, so having the website was an easier option and less confronting. People

who helped were also able to determine their own capacity, which was less burdensome. Thanks our providing such a service – I know it won’t be the last time we use it”.



gathermycrew.org

VWD: debunking myths & raising global awareness

Does Von Willebrand disease (VWD) only affect women? Is heavy menstrual bleeding normal? Is hemophilia more prevalent than VWD?

VWD is the most common bleeding disorder—but it's not as well-known as other bleeding disorders and perhaps because of this it is severely underdiagnosed. Patients often feel frustrated that their disease is not being properly recognised and many feel isolated because of this. Simply put: there is a lack of education on what VWD is and how patients are impacted.

During the 2018 Global National Member Organisation (NMO) training, held before the World Federation of Hemophilia (WFH) World Congress in Glasgow, Scotland, many participants were interested to learn more about Von Willebrand Disease. One attendee remarked, "I didn't know that VWD affects both men and women equally and I didn't know very much about the disease. I thought it was like haemophilia."

One patient with VWD said, "Von Willebrand Disease is a total separate disease from haemophilia." There is much to do to increase awareness of VWD and to improve management of the disease.

The WFH is leading global efforts to raise more awareness of VWD and increase diagnosis through the VWD Initiative Program and the VWD Global group. This year, the WFH developed a global Call to Action, and asked all national member organisations to sign on as a part of their commitment to integrate VWD into their work and to raise awareness of the disease.

Each NMO of the WFH is invited to sign onto this Call to Action to acknowledge the work that needs to be done, to make a commitment to recognising VWD and other rare bleeding disorders by taking action to create awareness, and to offer resources and provide support to improve the lives of those living with VWD. So far, ten NMOs have signed on to

the initiative.

NMOs can implement a number of measures in order to better integrate VWD into their work and to raise awareness for the condition. For example, they can organise a talk with patients and families on what VWD is; write articles in a newsletter, blog or on social media; or liaise with a haemophilia treatment center to educate and support parents.

NMOs can also add VWD in their advocacy efforts, perhaps by creating a VWD focused committee in their organisations. This would be particularly valuable way to destigmatise VWD in countries where blood is a taboo subject.

For more information, please go to the, "Join Us in the Global VWD Call to Action" page on the WFH website. www.wfh.org

All bleeding disorders matter. By working together to improve the quality of life of all people with bleeding disorders—including VWD—our community becomes stronger and more united.

By Luisa Durante
World Federation Hemophilia

Reprinted with permission
from WFH



NMO's signing on for the Global 'Call for Action'



GLOBAL VWD CALL TO ACTION

...and what WE can do
on a local level

You may notice that HFA is now starting to use the term von Willebrand disease for VWD instead of von Willebrand disorder. HFV will follow suit.

This is part of our commitment to align with the Global VWD Call to Action and the development of the VWD diagnostic and clinical management guidelines.

For many years the Australian bleeding disorders community has preferred the term von Willebrand disorder, although the medical diagnosis is von Willebrand disease. Our involvement in the global effort to standardise the VWD diagnostic guidelines means we are adopting the internationally accepted term von Willebrand disease, which is also used by the World Federation of Hemophilia.

The Call to Action asked for each national member organisation of the WFH (HFA for Australia) to sign the Call to Action to acknowledge the work that needs to be done, to make a commitment to recognising VWD and other rare bleeding disorders by taking action to create awareness, resources and provide support to improve the lives of those living with VWD. Such as:

- Organize a talk with patients/families on what is VWD
- Write an article in your newsletter, blog, website, social media on VWD
- Provide orientation and accompaniment to parents on VWD
- Adopt VWD as part of your organization's mandate
- Include VWD in your organization's advocacy efforts
- Any other action that brings awareness, education, or promotes conversation about VWD

HFV would like to kick start this **Call for Action** by asking any members with VWD to **share their story** with our community through the HFV magazine. HFV will also be looking at establishing a **peer support group for VWD**. If you are interested in being part of this group please contact julia@hfv.org.au and help shape development of this new and important group. (We already have a number of members with VWD interested in being involved).

See the back page!

**ARE YOU
AN EMPTY
NESTER?**

Has your son or daughter left home?
Please send us their address so we
can keep them connected with HFV!

**FREE MEMBERSHIP
FOR THEIR FIRST YEAR**
EMAIL: info@hfv.org.au
Grandparents and extended family
also invited to join!

PROBE Study update from HFA



Some of you have helped to test the print and online survey for the PROBE (Patient Reported Outcomes Burdens and Experiences) study. This is a multi-national study on the impact of living with a bleeding disorder, treatment outcomes and quality of life. HFA has joined other haemophilia organisations around the world to participate in this study and build a collection of robust patient-reported data – crucial to help HFA understand current issues for our community, and to quantify and represent these issues to governments or treatment and service funding bodies in a credible way.

PHASE 2 RESULTS

21 countries participated in phase 2 of the PROBE study in 2016-17. This tested:

- Whether the survey questions would capture consistent responses if they were repeated twice in the same community (e.g. Australia)
- The stability of the online survey

Australia contributed a total of 103 survey participants.

People with haemophilia/carry the gene – 51 (required = 50)

People without a bleeding disorder (controls) – 52 (required = 50)

An important learning from this phase was that larger numbers of survey participants will be needed at a country level to provide meaningful data. Participants were grouped as controls and into haemophilia severity, eg mild/moderate/severe. When comparing the different groups of participants, the sample sizes were found to be too small for stable results at a country level, but could be demonstrated at a regional level – for Australia, this was the Western Pacific Region, including Japan, Vietnam, Australia and New Zealand.

The results validating the PROBE study at a regional level are available on the PROBE study website – www.probestudy.org. Feedback about the online survey has been used to fix bugs and make enhancements for the phase 3 version. The international team set up a simple and user-friendly dashboard to display the country and region data for the participating national haemophilia organisations. Testing the dashboard and providing feedback was an exciting time for us as we realised the great potential of this data for HFA – both to understand the issues for our community and represent them to funding bodies and decision-makers. This questionnaire is about haemophilia, but a survey on VWD is also planned for the future.

NEXT STEPS

Phase 3 is planned to begin at the end of 2018. It is the final 'real world' stage of implementing the haemophilia survey around the world – where we invite the wider Australian bleeding disorders community to complete the questionnaire. This will be Australia's opportunity to collect current data about the experience of our community. As you can see, it will be important to gather as many survey responses as possible. Surveys will be available in print and online. Stay tuned for more information!

Our thanks to Dr Liz Bishop, Michael Kirby Centre for Public Health and Human Rights, Monash University who continues to provide oversight of the ethical process.

For more information about the PROBE study in Australia, visit the PROBE section on the HFA website - <https://www.haemophilia.org.au/research/probe-study>.

Or contact Suzanne O'Callaghan at HFA:

E: socallaghan@haemophilia.org.au T: 1800 807 173

Walk for BLEEDING DISORDERS



We are proud to announce the success of our Inaugural Walk for Bleeding Disorders with over 120 people booking in to join us on the day!

We were blessed with glorious sunshine and with the help of Marie and Scarlett waving their red scarves directing traffic most people made it to our meeting point!

We had a real mix of HFV members that we knew and first timers and friends of families with bleeding disorders. We should say a big thank you to the friends of little Fernando as there were many from the Brazilian community who attended to help support their friends.

Our President, Leonie, made a huge effort to attend the start of the walk, welcoming and thanking all for attending before dashing off to catch a plane to Europe!

Andrea and I stayed at the start line to cook up the sausages. What a fabulous sight it was for

us to see this sea of red making their way all the way around the lake!

We were really so delighted with the support we received on the day. With this being our first event we really had no idea how many people would rally to support us and we are delighted with the response.

We are now looking to grow this and have even more participants next year. So speak to your families and friends and let's see if we can make this event a huge highlight on our calendar!



TELEHEALTH & HAEMOPHILIA



Travelling long distances for appointments with children can be somewhat of a journey! It can mean time off work, long driving distances and may add to the stress for the patient and their families. Telehealth for patients who live in rural or regional Victoria, or even those who are interstate can be a great option.

The RCH HTC has been running telehealth appointments for sometime now, and now they are so much a part of our clinic that in every haemophilia clinic there are always one or two telehealth appointments. These appointments can be at the home of the patient or in the local doctors surgery – all that is required is the internet & a web-cam! A recent case of a

successful telehealth time was with one of our moderate haemophilia A patients (Tommy*), who had a bleed that required hospital admission and local administration of factor replacement. The next day we did a telehealth appointment with the patient, the family and the local doctor and we had great feedback from all involved. Tommy said he felt relieved to see some familiar faces on the computer screen, and his parents and the local doctor felt very supported and confident in the plan that we'd made as a team. It saved the family a 6 hour round trip to come down to RCH!

We appreciate the effort and commitment that families and persons with haemophilia make

to attend appointments, and whilst sometimes it is not possible to do telehealth, we are always on the lookout for suitable appointments to happen in your own home! Annual reviews need ideally to be in person for our severe haemophilia patients, therefore it is usually follow-up appointments that work well for telehealth.

Dr Sally Campbell
Haematology Fellow
The Royal Children's Hospital
Melbourne

BOOKING OPENS EARLY 2019

HFV Community Camp 2019

...first weekend of the school holidays

FRI 5TH APRIL - SUN 7TH APRIL
ADANAC CYC, YARRA JUNCTION



You are invited to attend the 2019 HFV Community Camp at Adanac CYC. Yarra Junction in the beautiful Yarra Valley! Unwind in 13 acres of undulating parkland, manicured gardens, natural bush and a recreational lake. Enjoy the magnificent views over the Yarra Ranges whilst joining in the activities or watching all the action from the deck.

There are so many activities for the kids including a 200 metre long water slide down the side of the hill into the lake!

Don't forget this is a COMMUNITY CAMP so all members are invited. Over the last few years we have had a number of adult families, couples and singles join us for the weekend. It is a valuable experience for all who attend. Everyone has something valuable to offer in terms of connect, support and empower...so come and join us! You will have a wonderful time and make some life long connections within our wonderful community!



Bookings are essential and through TRYBOOKING.COM/ZTIG
(Bookings open on the 10th Dec)

GAPPING WITH VIETNAM:

Collaboration & strong bonds

This August I was lucky enough to go to Vietnam with the Haemophilia Treatment Centre (HTC) team from the Alfred. There has been a relationship between the Alfred HTC and haemophilia services in Vietnam for nearly 20 years. The World Federation of Hemophilia has supported the Vietnamese services in their GAP and Twinning programs. When reflecting on this trip, my question to myself was what could I bring to a country I don't know, with resource needs that I can't meet. I also wanted to think about how this trip could contribute to the service that I provide to my work here in Melbourne.

HAEMOPHILIA SERVICES

The hospitals in Vietnam seem familiar yet also really different. The teams looking after the patients consisted of doctors, nurses, and to a small extent, allied health, comprising social workers and physios. I was struck by the closeness and lack of space. In one hospital visitors were limited to only one per patient. There was no privacy, but there was a warmth in the rooms that I was lucky enough to visit. The team knew all about their patients and the treatment that they needed. Laughter and support were common and there was a lot of sharing of experiences.

My frustration was that I couldn't talk to the patients unless there was an interpreter as most patients didn't speak any English. Learning to say 'Xin Chào', 'hello' in Vietnamese, was a great ice breaker, and even the small kids were helping me with my pronunciation.

Hand gestures, and games were another way that the barriers were broken down. Activities during our visit included challenges to solve in teams, involving toys and a parachute, and one of the most powerful aspects of my time in Vietnam was seeing the collaboration, and strong bonds between patients and their hospital teams.

SOCIAL WORK

There are similarities and differences between social workers across the two different countries. Social work in Australia is an established and respected career. In Vietnam it is an emerging concept. There are few social workers, and many are not trained in social work; they have come to work in their position through other pathways, such as nursing or administration. A key role of the social workers in Vietnam is dealing with funding for health care.

Without their assistance many patients would not be able to receive the treatment that they need: some-



times it is the trip to the hospital itself that is unmanageable. By comparison, in Australia we are able to provide treatment to everyone in an emergency and all citizens receive home treatment if they need it. As a social worker I am able to help patients with psychological issues, emotions, family relationships, and all manner of practical challenges, as well as supporting them to manage financial barriers to treatment



and care. I felt so fortunate to work in Australia, within a comparatively well-resourced service.

EDUCATION SESSIONS

While we were there, the Alfred team gave many education sessions on treatment and care that we had tailored for the teams in Vietnam. I spoke about social work concepts and the way that we work with individuals and families in Australia. The Social Workers were keen to hear about psychological interventions, and are starting to realize that this work is valuable, and enables patients to recover faster, use less resources and feel better in themselves. They are also becoming aware of the particular impact of having haemophilia. One of the most positive aspects of their program is the development of the Vietnam Hemophilia Association. I met a number of young men for whom this was enabling them to develop links and develop confidence, find career paths suitable to their health and make friends with others who have had similar experience through their life with haemophilia, for example having mothers who were super protective, or missing out on activities at school.

I had a brief session with social workers in Hanoi looking at how they work and I was very impressed both with their knowledge of their patients, and the large numbers of patients that they work with.

I am looking forward to continuing my relationships and work with the Vietnamese haemophilia social workers.

Jane Portnoy
Social Worker, Haemophilia & Other Inherited Bleeding Disorders, Alfred Health



relaxation meditation mindfulness

GUYS WITH MEN'S

are invited to attend the
 Haemophilia Foundation Victoria

2019

RETREAT

BLEEDING DISORDERS

FRI 15 – SUN 17 MARCH, 2019
 LOCHINVER FARM HOMESTEAD, CARISBROOK
 FOOD & ACCOMMODATION PROVIDED BY HFV

bookings essential through trybooking
www.trybooking.com/xuto



REGIONAL VISITS 2018

What a year for our Regional Visits Program. After a tour of Victoria and the opportunity to meet up with many of our members, our committee and staff feel that we have reconnected with our regional and rural members and have gained a better understanding of the challenges you are facing. We have met with people with mild, moderate and severe haemophilia, women and boys with vWD and number of people with platelet disorders.

We finished our visits in September with a trip to Horsham and Ararat. We are well aware of the distances our regional members have to travel for their healthcare needs but the 4 hour drive to Horsham was a bold reminder that this is the norm for many in our community. HFV committee member Dan Korn also joined us for the visit and Dan needed to allow extra time to stretch his legs and give his joints a break. Another reminder to us of the impact of travel on our community.

Once we arrived in Horsham we met with a lovely couple who had travelled 45 minutes to join us for brunch. They shared their journey with us and the challenges they face living in a small community nearly 5 hours from The Alfred. When John* was contending with

just his haemophilia the occasional trip to the Alfred was manageable and had been well considered before their move to the country. However John had recently developed a number of other health issues and the impact of constant travel back and forth to Melbourne for treatment was a huge challenge for John and his family.



The cost was also a burden at a time when he was unable to work. John's wife felt very isolated in her journey and had the challenge of managing work, small children and caring for her husband. Their experiences made a huge impression on us as committee and staff and served as a reminder that we don't know what the future holds - we can be affected by other illnesses or conditions despite having a bleeding disorder.

We need to develop more support mechanisms for people within our community such as a Partners Group. Many of our families with children with bleeding disorders are well connected and supported

within our community but there is a gap for partners of the those facing challenging times.

After Horsham we headed to Ararat and met with a number of people from our community. We heard about the challenges of ageing with haemophilia, and the pain management associated with that and possible joint replacements. There were challenges with unemployment that is not uncommon in regional towns. We met with a lady who had both haemophilia and von Willebrand Disease in her family.

From all the people we met not only in Horsham and Ararat but throughout all our regional visits we saw resilience, determination and a willingness and ease to connect with us.

We thank you for the support we have received during the year and are very grateful for all that we have learnt about the challenges you face and successes you have had along the way. We are still continuing to work on some of the issues that were raised and endeavour to remain relevant to all our members.

* Name changed for privacy.





Thanks to all who came and supported HFV for our 2018 AGM and enjoyed a fun day out at Myuna Farm! Our new committee was elected for 2018/19 comprising of Leonie Demos, Sharron Inglis, Zev Fishman, Karen Donaldson, Donna Field, Robyn Heal, Dan Korn and Ericka Mudie.

We still have position open to fill on the committee. If you have any interest in joining the team please contact HFV office on 9555 7595 and we can provide you with further details about what is involved. Our meetings are bi-monthly and regional /rural members can easily engage through teleconferencing.

The committee are made up of a group of people just like you either living with a bleeding disorder or caring for someone with a bleeding disorder. It gives you a good insight into how the foundation works and an opportunity to have input into how we connect, support and empower our community. The commitment expectation is very manageable and you'll have a lot of fun along the way!

ASK US...

Q & A's with Alex & Jane

QUESTIONS FOR THE ALFRED HTC TEAM

Are you a country patient?

I live about 2 hours from Melbourne and when I attend the HTC it is quite an expensive venture. Am I able to recoup some costs from anywhere?

Any patient living more than 100 kms from the CBD of Melbourne can apply for reimbursement of the trip down and back to/from their home address to see a medical specialist not available in your home town/city.

You must be a permanent resident in the rural town/city you are traveling from.

In Victoria the scheme is called Victorian Patient Travel Assistance Scheme (VPTAS). You can obtain a form from the social worker(s) at the HTC when you attend the Alfred Hospital or from reception of the Patient & Family Services Department (Social Work) located behind the cafeteria area in the ground floor. Your social worker Jane and Alex can sign the form if you attend the HTC appointment and they or Susan at the HTC reception, will ensure Dr Tran's details are completed before you leave.

If you are attending other clinics (i.e. orthopaedics, liver clinic etc) during the visit, please ensure you have a separate VPTAS form that requires the signature of the treating doctor you see and ensure they complete their full details, especially their medical provider number.

Also if your appointments are spread over several consecutive days and you need to stay overnight, you can also recoup some of the hotel room cost (not the full amount).

People receiving VPTAS assistance pay the first \$100 each treatment year for their travel and accommodation, except for primary card holders of a Pensioner Concession Card or Health Care Card. After the initial payment

VPTAS covers all travel and accommodation costs for the remainder of the treatment year.

A treatment year starts from the date of the first appointment with a specialist.

TRAVEL ASSISTANCE

People who are eligible for travel support will receive:

- 21 cents per kilometre for travel if a private car is used
- full economy-class fare reimbursements for public transport
- air travel reimbursement - only if the journey exceeds 350 kilometres one way and a commercial flight is used
- taxi travel reimbursement - only to or from the nearest public transport when there are no other transport options.

Follow this link to the website so you understand your eligibility.

<https://www2.health.vic.gov.au/hospitals-and-health-services/rural-health/vptas-how-to-apply>

Similar schemes exist in other states and for those living close to the NSW/Victorian boarder it

is known as IPTAAS as we often have patients traveling to the Melbourne HTC as its more convenient than Sydney.

<http://www.enable.health.nsw.gov.au/services/iptaas>



When I travel to the HTC, I need assistance so can I take my partner or someone from my family with me?

Yes an approved escort can travel with you. This needs to be signed off by your treating doctor. See section C of the claim form or in this link for more detail.

<https://www2.health.vic.gov.au/hospitals-and-health-services/rural-health/vptas-how-to-apply>

If the escort travels separately to you as the patient such as via ambulance or Flying Doctor Air Ambulance approval regarding the need of the escort is required through the following form.

<https://www2.health.vic.gov.au/about/publications/policiesandguidelines/VP-TAS-family-support-form>

Please discuss with the Alfred treating doctor when you attend.

What about accommodation near the Alfred HTC if I or my family need somewhere to stay?

The social work department can provide you with a list of surrounding hotels from Prahran to down on St Kilda Road. Please note though, that room rates vary and can be quite expensive. Again VPTAS is on a reimbursement system, so you need to be able to pay up front then lodge your claim form for a contribution refund.

If you are admitted to the Alfred, and your family members want to stay in Melbourne to visit you, there is a low cost accommodation option only available to family members. If you are on a pension or benefit, it is located in East Melbourne close to public transport. This must be booked ahead in most cases and costs claimed back from VP-TAS. Please discuss with Jane or Alex for further details.

ACCOMMODATION

Applicants may be able to receive accommodation assistance up to a maximum of \$45.00 per night (\$49.50 including GST). This may be available to the applicant and their approved escort if:

- they stay in commercial accommodation - that is, any accommodation that is registered as a business and has an Australian Business Number (ABN)
- the specialist completes the VPTAS claim form stating the number of nights of accommodation required
- the specialist approves that partner or carer can accompany the applicant (they must be 18 years of age or older).

**Alex Coombs & Jane Portnoy
Social Workers, Haemophilia &
Other Inherited Bleeding Disorders
Alfred Health**

HFV Noticeboard

To post a message on our noticeboard, please email our HFV office at info@hfv.org.au or call 9555 7595

ROYAL CHILDREN'S HOSPITAL

HAEMOPHILIA TEACHERS SEMINAR

2019

**\$30
PER
TEACHER**

You are invited to attend the
16th Haemophilia Teachers Seminar presented by the
Haemophilia Treatment Centre Team at the RCH.
Supported by Haemophilia Foundation Victoria

8.45AM - 12PM FRIDAY 15TH FEBRUARY
VERNON COLLINS THEATRE,
LEVEL 1, WEST BUILDING (YELLOW LIFTS)
ROYAL CHILDREN'S HOSPITAL

Bookings Essential through
TryBooking by 11th Feb
www.trybooking.com/427643

Speakers:
Dr Chris Barnes, Janine Furmedge (Haemophilia Nurse), Nicola Hamilton (Physiotherapist),
primary and secondary aged students with haemophilia

HFV BABY & TODDLER

GROUP

Establishing a baby and toddler group for families
with babies and young children with bleeding disorders

If you are keen to connect with other families with affected by bleeding disorders please email us your details and we can connect you directly.

We already have 2 families keen to connect with others so if you are interested please contact Julia Broadbent at HFV on 9555 7595 or email julia@hfv.org.au

DIARY *DATES*

HAEMOPHILIA TREATMENT CENTRES

DEC

20 HFV Office Closes

JAN

21 HFV Office re-opens

FEB

15 RCH Teacher's Seminar

MARCH

15-17 Men's Retreat

APRIL

5-7 HFV Community Camp

OCT

10-12 National Conference (Sydney)

13-19 Bleeding Disorders Awareness
Week

HENRY EKERT HAEMOPHILIA TREATMENT CENTRE

Royal Children's Hospital
Flemington Road, Parkville
P. (03) 9345 5099 E. he.htc@rch.org.au

Dr Chris Barnes | Director Henry Ekert HTC
Janine Furmedge | Clinical Nurse Consultant
Julia Ekert | Office Data & Product Manager
Nicola Hamilton | Physiotherapist
Wade Wright | Social Worker

RONALD SAWERS HAEMOPHILIA CENTRE

The Alfred
1st Floor, Sth Block -William Buckland Centre
Commercial Road, Melbourne 3004
P. (03) 9076 2178 E. [\(03\)haemophilia@alfred.org.au](mailto:(03)haemophilia@alfred.org.au)

Dr Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Emma Reiterer | Clinical Nurse
Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist
Diana Harte | Psychologist
Debra Belleli | Data Manager

**The HFV Committee and staff wish you a happy
and safe festive season.**

Thank you for your support during 2018 and we look
forward to working with you again in 2019.

The HFV office will close at midday on
Thursday 20th December 2018 and will reopen on
Monday 21st January 2019.

During that time if you have an urgent matter please
contact Julia Broadbent on 0410 247 908.

HFV MEMBER SERVICES & PEER SUPPORT

Membership Annual Fees:

Standard family membership

\$33.00

Concession member

\$16.50

Allied Member

\$16.50

Organisational member

\$55.00

* No joining fee for new members joining at the Standard Family Membership rate.

Ambulance Subscription Subsidy:

To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee.

(Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

To obtain an Ambulance Subsidy:

Forward subscription receipt (or a copy) to the HFV Office with your contact details. Subsidies will be paid on a reimbursement basis.

Other Subsidies:

- **MedicAlerts:** A subsidy of 50% of the first purchase price of any MedicAlert, (with the subsidy payment being up to \$30 in value and not including the annual fee) is now available. To obtain a subsidy, forward a cover letter and receipt to the HFV Office.

Live Well Funding:

Live Well Funding is open to all current financial members who can apply for funding for any activity or one off item that will assist in the management of their conditions such as mobility support aids, meditation, massage etc.

Care and Counselling:

This is available through your treatment centre.

Magazine:

Your quarterly magazine offers information and details of upcoming events.

Website - www.hfv.org.au

The HFV Office:

The office is usually open from 8.30 am to 4.30 pm Monday to Thursday. If you plan to come to the office, we suggest you ring ahead to check if the office is staffed.

We are located at 13 Keith Street, Hampton East, Victoria, 3188.

Phone: (03) 9555 7595

Fax: (03) 9555 7375

Website: www.hfv.org.au

Email: info@hfv.org.au

MEN'S GROUP

Our current group meet for their Annual Men's Retreat – a much needed weekend away that included massages, relaxation and meditation. In 2018, eleven members attended the retreat, including a number of first timers, all promising to return after making powerful connections with their peers. There are also opportunities to meet for brunch and lunch during the year.

WOMEN'S GROUP

The group meets once a year over lunch and usually get to enjoy an event with a twist. Our most recent event our ladies spent a day learning how to tango and enjoyed a beautiful tapas meal together.

They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant...to name but a few.

YOUTH GROUP

The Youth Group aim to meet up a few times a year usually based around an activity like laser skirmish or bowling and then head out for lunch.

We also have our actively involved Youth Leaders who are present at our family camp. They attend specific youth leadership training led by our formally trained youth leaders – an initiative developed by the leaders themselves.

GRANDPARENTS GROUP

The Grandparents and Friends lunch is a great opportunity to connect with all the grandparents and share the company, stories and experiences so please come along and enjoy the day. Lunch is provided by HFV and the company is always good!

The initial impact of haemophilia can be a traumatic and stressful time in our lives and interaction with other grandparents can be a reassuring and rewarding experience.

BOYS GROUP

Our Boys Toys Day Out is a wonderful opportunity for our boys to get together with other boys with haemophilia or related bleeding disorders and to spend the day with their dad or another significant male in their lives...grandfathers, uncles or family friend. Previously our Boys Toys events have included fishing trips, Go-Karting, Laser Tag and Tree Top Adventures.



DO YOU HAVE VON WILLEBRAND DISEASE?

We are looking at ways to connect people with vWD through a new peer support group.

Please contact HFV and tell us what type of peer support would work best for you ie face to face, via email, conference call and any other suggestions you may have.

email: julia@hfv.org.au or phone 03 9555 7595

