

Factor Matters

Haemophilia
Foundation
NSW



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Autumn 2019

Volume 39



What a great start to the year!

Its **World Haemophilia Day** on
17 April 2019. See Page 11.



About Us

HFNSW is a member driven not for profit organisation that provides support programs and advocacy for the NSW bleeding disorders community, their families and carers. While specialist doctors and nurses provide world class medical and social care for our members, our mandate is to support the full range of other important things for the bleeding disorder community such as: community participation, physical & emotional support, advocacy, education and financial assistance to members, their families and carers.

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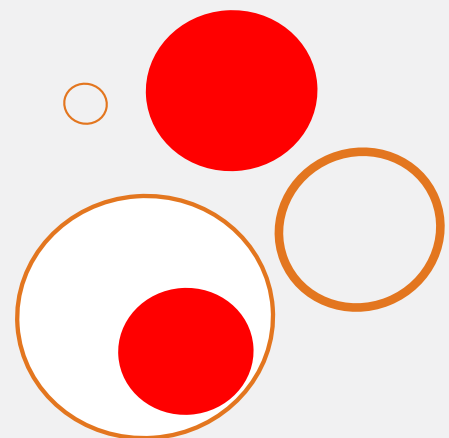
In This Issue

- p. 3 A Word from the President...
- p. 4-5 Living like a Swede - Mindi Palm
- p. 6-8 Planning for a successful HTC visit
- p. 8 Tom Walsh Art Exhibition
- p. 9 2019 Conference
- p. 10 Event wrap up - Family get together
- p. 11 Pizza Party / WHD / News events & dates
- p. 12 Haemophilia Centres & HFNSW Member Service

On the cover: Family Day



Read more about conference being hosted in Sydney this year



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Dan Credazzi – President Haemophilia Foundation New South Wales

Since our last newsletter, there are developments in our pursuit of access to longer acting treatments. Gene therapy trials for F8 and F9 deficiencies are also underway globally and some of the clinical trials

are taking place in Australian trial sites. These are fantastic developments which present life changing opportunities for some sections of our community.

Definitely something to discuss with your haematologist during your next clinic visit. But new therapies aren't for everyone, and some will take a long time before they reach us. Due to the advocacy of your community which resonated around the country with the other State & Territory Foundations, HFA pursued and gained a federal grant for an Ageing specific project focused on assessing and supporting the needs of our ageing members. This deeper focus into ageing in the bleeding disorders community will help us collect the information needed to help government adjust or add services and for haemophilia foundations to ensure they are meeting needs. The plan is to not only develop a deeper understanding of the needs of people who are ageing, and their carers and families, but education resources will be developed as part of the project. This deeper community focus follows on last year's spotlight on females with bleeding disorders. We hear you and things are getting done.

For the first time in a long time, your volunteer Foundation management committee is more fully reflective of our community members than ever before. We have young & old, male & female, patient, clinician & parent, rare & rarer all represented. So this provides for well informed and more credible representation and advocacy at our community meetings, to HFA and to governments.

The National Conference is on this year in Sydney and given the new science and treatments, this will be one of the most fascinating conferences ever. Contact our office if you need help with registration fees or transportation. And thanks to all of you who attended our recent NSW events in Sydney and Newcastle. Both events went very well, and we aim to hold them regularly so our community comes together to support one another. Thanks to Tony and Natasha at HFA for making events happen from idea to execution.

And thanks to HFNSW member Sam Duffield who recently travelled to Myanmar with Leonie Demos (HFV President) on behalf of HFA to meet with the Myanmar Haemophilia Patient Association to discuss the potential for a twinning partnership between the patient groups in Australia and Myanmar. Sam and Leonie also met with some of the doctors who treat people with haemophilia and learned that currently, there is just 200,000 iu of factor available in the country which has a population of over 50 million. We look forward to the next steps for this important World Federation of Hemophilia initiative to strengthen the foundations of treatment and care in this very under-served area of the world. I hope we will be able to assist! Keep an eye out for further reports from Sam and others about the progress of this twinning partnership.

Some of your committee members and I attended NSW Equity Fest where we collaborated with other NSW Health sponsored groups like ourselves. These connections strengthen our own capabilities and connect us with other smaller organisations which haven't been around as long as HFNSW.

Dan Credazzi

President, Haemophilia Foundation NSW

Amanda (Mindi) Palm is a former Australian community member and blogger, now living in Sweden

We've had three years of haemophilia management at our Haemophilia Treatment Centre at Westmead Children's Hospital, NSW, working closely with our haemophilia nurse Robyn who has become a wonderful friend and support to our family.

Sadly, we said our final goodbyes in July 2018 before we embarked on a new journey and chapter to live in Stockholm, Sweden and learn to 'do as the Swedes do' with groovy ABBA music playing in the background.

Our son Elias was diagnosed with severe haemophilia A as an eight-month-old baby in 2015 and had received factor 'on demand' intermittently when we were living in Australia.

Upon our first visit to The Karolinska University Hospital here in Solna, Stockholm we learnt a few things. Firstly, there is a panel of haemophilia doctors and nurses who regularly meet and make decisions for their patients based on group consensus. Children with haemophilia receive a dedicated carer at pre-school, funded wholly by the local government, hence why the taxes are so high!

Incidentally, we learnt that the longest word in all of medical history is: Barnkoagulationsmottagningen. Did you get that? It's the Swedish word for 'children's coagulation centre.' Now that's a mouthful!

Our family has started the process of learning how to give Elias factor intravenously, so not only is our Little Bleeder learning to get comfortable with needles, but he's also how to speak and act like a Swede!

Until the next update, hej då!

Moving to Sweden

Mindi took the time to answer a few of HFA's questions about the move to Sweden.

HFA: What did you do with the Sydney and Stockholm Haemophilia Treatment Centres (HTCs) to prepare for the move?

Mindi: I consulted with our HTC Nurse, Robyn Shoemark, and haemophilia doctor, Dr Juliana Teo, at the Children's Hospital at Westmead who had a final consultation, blood test and wrote up a letter for us to give to our haematologist here in Sweden. Elias, our son, and Lucy, our daughter, both had bloods taken for final factor level testing and then (somehow) Robyn managed to find the clinic we attend now, '**Barnkoagulationsmottagningen**' in Solna, Stockholm.

In the first few weeks we arrived, Elias had several incidents where he was bleeding through the nose, in the mouth and he had a swollen and bruised foot. So I commissioned my husband Tommy to go in for the first consult as it was considered an emergency and I was really in no state to handle it all - in Swedish! He gave them the letter from the HTC at Westmead and from there we started having regular consults. All children in Sweden - citizens, residents, and immigrants - are covered by the government for free access to healthcare, dentistry and medicine, so that was not an issue.

HFA: How did you manage the plane flights and international travel?

Mindi: Though not recommended, we opted to not have insurance as we had only one stop-over in Bangkok and straight onto Stockholm. So we just decided, it's a straight flight there and hopefully we wouldn't run into problems. Each time we travel overseas Robyn writes us a letter and we take that with us along with a supply of medication, which gets checked at every security gate. It's no problem taking it with us and, as we have the letter, there are no problems with international customs.

HFA: What is different for you and Elias in relation to haemophilia and care in Sweden?

Mindi: A marked difference is that our local government or 'kommun' issues a specific carer/aid person in Elias' pre-school to help watch him for any incidents. This is certainly new to us, as there is no funding for these kind of resources in Australia.



Elias and Robyn at the HTC in Australia



Elias outside the HTC in Sweden

Photos: Mindi Palm

Reprinted from National Haemophilia, No 204 December 2018

Jaime Chase is Haematology Clinical Nurse Specialist and Veronica Oakley is Haematology Child Life Therapist at John Hunter Children's Hospital, Newcastle, NSW.

Teaching and supporting children with haemophilia.

Jaime Chase and Veronica Oakley

Tom is 5 years old and has mild haemophilia A. He has had a minimal number of injuries in the past that have required the intervention of factor. He is normally very happy to come in to his Haemophilia Treatment Centre (HTC) to see staff and looks curiously at staff if he does require treatment.

Tom was wrestling with his brother 3 days ago and has a swollen shin on his left leg. He presented to the hospital over the weekend and has had two doses of factor, each on consecutive days. On arrival to the HTC for review and a likely third dose of factor he is clingy to his caregiver and panicky about the possibility of more factor...

A child with haemophilia passes through many stages of childhood, as does any child. Generally, a child's ability to understand their disorder will relate directly to the stage of childhood they are currently experiencing. Babies to adolescents all have different needs and requirements both for learning about their haemophilia and how to manage their treatment.

Child Life therapy or **play therapy** is therapy offered by specialist professionals across many children's hospitals across Australia. Child Life Specialists work with other health care staff to adequately prepare children and families in hospitals and other settings to cope with hospitalisation, procedures and understanding their condition. The Child Life Specialist has an extensive knowledge about the differing stages of child development and how each stage can affect treatment. At John Hunter Children's Hospital the Haematology Child Life Therapist has been working with the Haematology Clinical Nurse Specialist to develop specific activities to support children with haemophilia.

One way of supporting a child with haemophilia we have been exploring is the utilisation of a **busy bag**. This play or activity bag is one that comes with the child to the HTC or hospital and is used at home for infusions. This bag of activities has specific play items in it only to be used for hospital or treatment days. Devices can

have specific apps that are only used on these days. The bags described below are designed specifically for each developmental stage that children to adolescent's experience.

BABIES (UP TO ONE YEAR)



Babies need comfort and support during their infusions and examinations. This may mean a position of comfort for the baby, where the parent holds the baby in a specific position to allow a hugging hold. This hold gives comfort and security while giving health care staff safe access to the child for infusions and examination of limbs. The

upright position promotes a sense of control for the child. The utilisation of calming music and distractions such as bubbles can also be useful. The introduction of picture books about factor and infusions can be beneficial at this time.

Busy Bag Contents

- Pacifier (dummy, cuddly etc)
- Bubbles
- Special toys that are only used for HTC trips and infusions
- Calming music

BABIES (UP TO ONE YEAR)



Toddlers of this age understand their world through touching, seeing and hearing. We know that toddlers do not understand cause and effect, so they are often very surprised that an adventure has ended up in their HTC.

Comfort for the toddler remains paramount at this time, so a position of comfort is very important,

as is the nomination of one voice – nominating one person only to speak to the child. To enhance the child's sense of security, a parent who has been educated on what will happen prior to the intervention is ideal to

talk during the procedure. This allows the child to feel secure and validated and gives positive reinforcement. The involvement of parents/caregivers is vital. Using numbing cream pre-infusion and distraction can be beneficial at this time.

As soon as the child is able, they should be involved in the procedure - holding band-aids® and helping staff set up (if appropriate). The use of medical kits to play with at home are encouraged as are the continued reading of board books about haemophilia.

Toddlers will also benefit (if able) from a trip to the HTC when nothing happens. The opportunity to come to a centre and have no infusions and play is very comforting to the toddler and may allay fear that the HTC is a place where you always get held and are given infusions.

Busy Bag Contents

- Cuddly toy (if wanted)
- Special busy toy
- Bubbles
- Specific App on IPAD/ phone that is only used for HTC trips/ infusions
- Calming Music
- Making a small photo book of the child's trips to hospital can also be beneficial

PRESCHOOL (3 TO 7 YEARS)



Children of this age group have what is called 'magical thinking'. This can be explained as the six-year-old who only draws from his own experiences to explain the world around him. When asked what is haemophilia, he may reply

'when I get hurt and need a needle'. Pre-schoolers are very egocentric - meaning that they understand that these things are happening to them but do not have the capacity to know that what happens to a doll might happen to them. Preparation toys at home and practicing factor administration are very successful for this age group.

Positions of comfort are still very important during this age group as is the involvement of the children in setting up for their procedure and asking them to hold band-aids etc. Numbing cream (if used) remains important as do distraction techniques.

Education involves the reading of books, making a social story about going to hospital and the use of colouring in pages. A medical kit at home and time spent acting out infusion scenarios can be beneficial, with play being directed and initiated by the child. Trips to the HTC that do not require treatment are also beneficial at this age.

Busy Bag Contents

- Cuddly toy
- Art and/ or craft activity
- Playdough
- Special app on device
- Using a photo book to document experiences

SCHOOL-AGED (7 TO 11 YEARS)



This age group is entering into the realm of logical thinking - meaning that they can start to think in a step-by-step process. This enables them to start to think about self-infusion. They are less egocentric in the way that they view the world - this is

when demonstrating on a doll or arm makes sense to the child. School-aged children are able to read more and understand relevant teaching steps.

This age group is perfect for books and simplified teaching about their haemophilia. Encourage participation in the transfusion process - working towards self-infusion. Involve the child in decision-making regarding sports and activities that may be offered and ask for their input early about activities offered. This can mitigate the way that children approach sporting activities and perhaps making the wrong decisions about what lunchtime sport they should join in for.

Busy Bag Contents

- Special cuddly toy
- Craft/ building activities
- IPAD/device
- Music devices
- Knowledge of deep breathing and visualisations.

ADOLESCENT (11 YEARS AND OVER)



Adolescence is an area of great growth and with this brings opportunities for learning, experiences and experimentation. Adolescents continue to be able to think logically (step-by-step) and to understand that there are consequences for their actions.

Talk openly and honestly with the adolescent about both their treatment and

their plans for the future. This is the age where most adolescents are self-infusing and starting to take control of their own haemophilia.

Busy Bag Contents

- Personal devices
- Knowledge of deep breathing/visualisations
- Specific games activity - cards etc.

If we look back to the example of 'Tom' given in the first paragraph, we can see a child who is worried and

nervous about the possibility of factor. Luckily, he didn't need any more factor that day and the experience was turned into a positive one with a trip to the Starlight room and spending time playing with nursing staff before leaving the Unit. This positive experience was very beneficial to Tom

The utilisation of play in the ongoing care of children and adolescents with haemophilia is important to promote trusting relationships with healthcare providers.

If you have any questions, please see your local HTC for further information.

FURTHER READING

Association of Child Life Therapists Australia - Childlife.org.au

Child Development:

The Center for Parenting Education - centerforparentingeducation.org

Child Development Institute - childdevelopmentinfo.com

Reprinted from National Haemophilia, No 205 March 2019

TOM WALSH ART EXHIBITION

Congratulations to Tom who showcased his work at his art exhibition again this year. You may remember reading about Tom in Factor Matters, Vol 35: Autumn 2017. He also has generously donated two major pieces to RPA HTC.

Beyond another well received and successful showing, further congratulations to Tom on gaining a place at the National Art School, Sydney. We look forward to keep following your journey and successes.



19th Australian Conference on haemophilia, VWD & rare bleeding disorders *Challenging the Status Quo*



The 19th Australian Conference on haemophilia, VWD & rare bleeding disorders will be held at the Novotel Manly, Sydney, 10-12 October 2019.

Our conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

The conference is a great opportunity for people with a bleeding disorder and their families - parents, siblings, partners - to attend, learn more information about new treatments, gene therapy, children and young people, sport and living with a bleeding disorder etc..., make connections and become better empowered about your health.

COMMUNITY FUNDING

To assist, HFA has allocated funding to assist community members with expenses to attend the Conference. For details and an application form for part HFA funding go to www.haemophilia.org.au/conferences or call HFA on 1800 807 173 for a form to be emailed or posted.

Conference subsidies will be available to assist **HFNSW members** to attend the conference. Please register your interest by emailing coordinator@hfnsw.org.au or call 0470 637 928

MORE INFORMATION

Visit www.haemophilia.org.au/conferences.

EVENT WRAP UP - FAMILY GET TOGETHER

It was lovely to see many faces (new and old) at the first family get together in Sydney for the year. The location was fantastic at Blaxland Parklands and the kids were able to play on the numerous outdoor activities and then we all went on a train tour of the Newington Armory which was fascinating. Natashaia Coco from Haemophilia Foundation Australia and Robyn Shoemark from Westmead attended, it was great to have them there. Thank you to everyone who attended and for those that missed out we will host another one soon.



We had a great turn out to the Mario Kart & Pizza Party for a fun “adult” free afternoon. We talked about looking after your disorder and most importantly hosted the first Mario Kart challenge. The day was a great afternoon for the boys to meet one another, and in some cases the first time they had met anyone with a bleeding disorder, and talk about taking control and transition. Thank you to HFNSW for financially supporting the afternoon.

Jaime Chase, Haematology Clinical Nurse Specialist at the John Hunter Children's Hospital



Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease

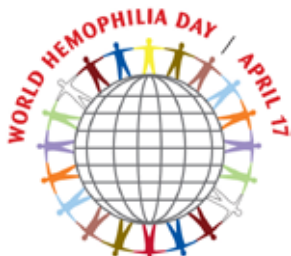
and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

Reach out and connect to your community!

Reach out to others in the bleeding disorders community. Take opportunities to meet others with similar experiences and share your stories and tips. No matter your age or stage, connection throughout life is vital.

NEWS, EVENTS AND DATES FOR YOUR DIARY ●

World Haemophilia Day – 17 April 2019



In Sydney we have the Sydney Town Hall and Pfizer HQ (Barrack Place, 151 Clarence St Sydney) turning red at sun down in support of World Haemophilia Day. Show your support on the night, and post photos on our Facebook page of you and your friends at the landmark. #WHD2019

19th Australian Conference on haemophilia, VWD & rare bleeding disorders

Novotel Manly, Sydney - 10-12 October 2019
www.haemophilia.org.au/conferences

Bleeding Disorders Awareness Week - 13-19 October 2019

www.haemophilia.org.au/bdaw

HFNSW Camp - 8-10 November 2019

www.hfnsw.org.au

**remember you can check the news and dates on our website
www.hfnsw.org.au*



Is HFNSW meeting your needs? Either way we would love to hear from you, feel free to email us on coordinator@hfnsw.org.au. We are looking at the 2019 calendar and trying to meet all the needs of our vast community. Are you interested in:

- Young mums group
- Men's Group
- Women's Group (for parents, carers and womens with bleeding disorders)
- Youth group
- Family catch up's

HAEMOPHILIA CENTRES

Kids Factor Zone

The Children's Hospital at Westmead

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HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

HFNSW Annual Family Camp: free of charge for people with bleeding disorders and their families

Newsletter: Your newsletters from HFNSW and HFA offer information and details of events, personal stories, education, treatment information, etc.

Financial Assistance: MedicAlert Bracelets, Shoe rebates, Travel assistance, Education & Training, grants.

Information and Support:

-Education and assistance to members with bleeding disorders and those who also have HIV

-Provide tutors and entertainment to members who might require extended hospitalisation

-Information and social activities for members and their families

-Rural visits to areas of NSW where there are no specialists

HFNSW COMMITTEE...

Being a member driven organisation, the committee is always interested in hearing from its members, community, friends and family. If you want to have a say in how the Foundation delivers its service and shapes its future, please contact the office at coordinator@hfnsw.org.au

Committee meetings held monthly

HFNSW Committee Group



*Craig Haran,
HFNSW Committee Member*

