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YOUTH Hⁱ

News

HAEMOPHILIA FOUNDATION AUSTRALIA

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MESSAGE FROM THE CO-CHAIRS

The 14th Australian & New Zealand Haemophilia Conference was held in October at the Hyatt Canberra. We were fortunate to have the opportunity to attend, along with other youth from around the nation and a few from New Zealand sharing ideas and networking. Conferences are a great opportunity to meet new people and catch up with old friends.

This is a bumper issue highlighting the conference and feedback from each of the committee members that attended. For full copies of the presentations visit www.haemophilia.org.au/conferences.

On behalf of the Youth Committee, we wish you and your families a safe and happy festive season.

Paul Bonner and Robert McCabe



CONFERENCE REPORTS

Anna Szytyer, Women's Wisdom

Belinda Burnett (NZ) shared her story about being the mother of a daughter with severe haemophilia A. She spoke of her heartaches and battles with medical professionals over the years. It was encouraging to hear the progress that has been made to enable people with haemophilia to lead as normal lives as possible – including travel! Though, never underestimate the power of thorough planning before departure.

The next speaker, Dr Susan Russell (Sydney Children's Hospital) presented information about the management of delivery in carriers and management of the newborn with haemophilia. Things need to be carefully planned in advance to ensure minimal stress and injury to mother and baby. Nowadays, hospitals are well prepared for dealing with both mother and baby where there is a known case of haemophilia.

The final speaker in this session was Dr Julie Phillips (Wellington Hospital, NZ) who spoke about menorrhagia: best care and practice. It was surprising to learn the amount of women with, or carriers of, a bleeding disorder who required treatment for menorrhagia. Even more surprising was the lack of understanding of menorrhagia for women with, or carriers of, a bleeding disorder – with many of these women believing that their really heavy periods were 'normal' to all women. There are many options available for treating women who suffer from menorrhagia so their condition can be dealt with so that their 'bleeding' does not impact on their daily lives. More importantly, there is an increasing awareness amongst haematologists and gynaecologists that women with bleeding disorders or carriers of a bleeding disorder do require specialist menorrhagia care.

Chantel Roberts, *Hepatitis C treatment and care*

Neil's presentation about his journey through Hepatitis C treatment was great. His account was personal and truthful, and described the highs and lows of treatment and in his case it was nice to hear the story had a happy ending! The rest of the session was very informative, explaining the different treatments and potential side effects, and other factors that can trigger symptoms of hepatitis C. before this, I wasn't aware of much about hep C treatment so this session was a real eye opener.

Craig Bardsley, *Better Health and Fitness: Laying the Foundation for Positive and Independent Management of Haemophilia* - Brendan Egan and Janine Furmedge

Brendan and Janine talked about people with bleeding disorders being able to participate in sport that once upon a time we would not have been able to play or advised not to. They highlighted the importance of safety equipment and the need to use prophylaxis before sport and if necessary treating afterwards.

It was great to hear how many people were treating at home which allows them to take control of their lives and their treatment. Knowing that kids at an early age (8-9) were taking responsibility for their treatment show just how far we have come from the old days when we had to present to A&E with every bleed.

Dale Spencer, *Hepatitis C treatment and care*

The session I most thoroughly enjoyed was the Hepatitis C talk by Neil Boal, Prof Geoffrey Farrell and Dr Stephen McNally. I found Neil's talk very positive for such a hard topic, I felt his personal struggle and I couldn't have imagined how hard it would have been dealing with haemophilia and hepatitis C. Through Neil's story, I can see the hard choices that need to be made about treatment and disclosure. Neil was very open and he shared his story from the patient's side which was a great lead-up for the medical profession to show supported evidence for the treatment, care and decisions about treatment with regards to work, studies and social life.

Treatment is hard work - Neil was successful with his 48 week treatment, which he says he wouldn't have done without the help of his partner. Some side effects of the treatment are lack of energy, numerous treatments and a major side effect can be depression. I can see how you have to plan for a time in your life that suits to begin treatment as it takes up a lot of time and can conflict with work, studies or other important roles.

Kristi Jorgenson, *Planning and managing best practice care and treatment*

The session focused on the planning and management of haemophilia care and treatment. This was particularly interesting in that it explained the advancements occurring in the development of the Australian Bleeding Disorder Registry (ABDR) which I believe will be a very beneficial tool in the care of people living with haemophilia.

Alison Turner spoke about the NBA which has only been around for 4 years. They coordinate the supply of blood products, and basically are here to ensure everyone has the treatment they need, when they need it. The efficiency of the NBA was put to the test last year when there was a shortage of plasma-derived factor VIII from within Australia. An agreement to supply imported product ensured that should a dire situation arise, treatment could be obtained from elsewhere.

Finally, Prof. Albert Farrugia spoke about the safety of products, which we know has been a problem in the past. If there is one thing that was a 'take home' message from his discussion, it was that safety must continue to be of critical importance, and constantly revisited.

Matt Blogg, *Youth Matters*

Dr Sarah Martin from the Canberra sexual health centre talked about health issues for young people living with a bleeding disorder, hepatitis C and/or HIV. She talked about disclosing personal and sensitive issues, when is the best time and how to approach the conversation and deal with their reaction.

Janine Furmedge and Brendan Egan from the Haemophilia treatment centre Royal Children's Hospital in Melbourne did a presentation on achieving better health and fitness and how people can manage haemophilia more independently. They talked about the importance of early home therapy, preparing for independence, and being able to maintain home therapy and travel. They also talked about the importance of normalising child development to enable participation in controlled sporting activities such as Auskick and structured sporting activities which suit the child.

Leonie Mudge, Haemophilia social worker from the Royal Prince Alfred Hospital in Sydney, talked about the planning that is needed for a smooth transition from paediatric hospital to adult hospitals. Some of the things she mentioned included the adolescent brain, the differences between Paediatric and Adult treatment centres, communication, respect and how young people might be worried about finding someone they can trust to talk to about the things that concern them.

Michael Lucken, *You won't die from laughing*

I walked into the plenary room and the stage was full of colour and just looked like lots of fun. Well that was a huge understatement. I could hardly stop myself from laughing, it was that good. Up on the stage we had Patricia Cameron-Hill and Dr. Shayne Yates. Patricia was great. Up and around bouncing all over the place. She would be moving non-stop, always had something funny to say that was relevant somehow to the life of someone with haemophilia, the health professionals or their carers. There was a lot of audience participation ranging from how to handle situations with a sense of humour to telling jokes, sharing life experiences and seeing the funny side of things. They played a skit two or three times, changing it differently each time just to show that different reactions can show different outcomes and that each outcome can change the mood and stress – for you and other people. One of the main points of the session was to show you that you can control your life, your moods and your stress levels by the way you react to people and situations and if you do it while laughing it will make things much better.

Paul Bonner, *Helping families to manage bleeding disorders*

This session brought back memories from when I was a kid, some of which I would much rather forget about. It made me happy to see the progress that has been made in the last 20 -25 years in understanding how children are cared for when in hospital. It is good to see that parents are taught and encouraged to become actively involved in their child's treatment, and learn techniques to minimize stress to their child and themselves during treatment so that the hospital experience is a happy one.

One thing that I was most impressed by was the number of young people from the bleeding disorders community that were involved in the conference by actively asking questions, chairing sessions or actually being speakers in the conference sessions.

Robert McCabe, *Conference Closing ...and what about the future?*

The final session at the conference focused on that age old problem, the future. The question, "How do we maintain and progress the level of haemophilia in Australia."

Given the varied group it involved much discussion about treatment products, inhibitors, gene therapy, specialist ongoing care services, and the list goes on.

If there was one thing that I felt confident in at the end of that session, was in the future. As I explained the only way to ensure that haemophilia care in Australia is effective, is for everyone to work together. This includes patients taking an interest in their own health and well being.

There has been a steady decline in participation with local member foundations, which still plays a very important function in maintaining services and support for people with haemophilia and their families.

The reason I am so confident about the future is the number of youth representatives participating in the session. Young people, boys and girls all effected by haemophilia in differing ways, not only took an interest in all of the conference sessions, but were actively participating in them.

Sam Duffield, *Helping families to manage bleeding disorders better*

At this session I realized that although times have changed, the fear of bleeds hasn't gone away – I learned more, not only about managing myself, and perhaps even my future family, but also about what my family has had to deal with in having me as a part of it! So, to all you young people out there, go easy on your parents - they love and care for you but just make sure you don't let them pamper you too much! Remember we still have to have some fun even if there is a risk of a bleed. Sorry, mums and dads out there but I had to say it!

Scott Christie, *Key Issues in haemophilia 1*

Dr Kathelijn Fischer delivered a strong message in her presentation on prophylactic treatment. The research & development that has been conducted into the benefits of prophylaxis at an earlier age compared to prophylaxis in the early teens, has certainly opened my eyes as a person with mild haemophilia. Prophylaxis at an earlier age minimises significant early bleeds and initial joint damage and highly increases quality of life. Young boys on early prophylaxis will benefit from normal participation in life activities, sport, social interaction etc. Not only does early prophylaxis give youth improved freedom to enjoy life, but it also reducing long term affects of haemophilia on the body (arthritic joints, joint replacements or joint fusion).

The presentation of pre-genetic diagnosis and IVF by Dr Penelope Foster I found was of particular interest to me and other young members of the haemophilia community as we consider the options of parenthood. There are a number of diagnostic and reproductive options that can be considered and used in better preparing new parents within our haemophilia community.

The general conversation amongst the youth after the session, discussed the ethical and moral considerations in making parenting decisions. Further discussion revolved around the procedures and the effects these may have on parents both physically and mentally. This was an important topic for young people with haemophilia & haemophilia carriers as they consider parenthood, weighing up the options to ensure that their future child has a better child "Quality of Life".

Simon McMenimum, *Key issues in haemophilia 1*

Prof. Ian Kerridge discussed what he termed 'Ethnomics'. 'Ethnomics' was where the wallet and the heart intersect. How much is too great a cost when it comes to health care? Where is the line in the sand that says 'your health care can cost this much but no more'? Are we approaching it or have we past it already and just not noticed? This is a topic which has always interested me. Haemophilia treatment and care in Australia is amongst the best in the world and is delivered to the patient without cost, but how long will that last and what about other nations that aren't as fortunate?

For more information about any of the above topics please talk to your health professional at your Haemophilia Treatment Centre.





HEP C INFO FOR YOUNG PEOPLE

Hepatitis Australia has just released this new web site. It's hard to keep up with all the latest info about hepatitis C and this web site covers a lot of common questions in a user-friendly layout. But beware – it has sound effects, so turn your sound down if you don't want to alarm your neighbours!

Some of the topics:

- How hep C is passed on
- How it affects people
- Do I have to tell anyone?
- How to manage your headspace
- Treatment
- Staying healthy
- Medicare and Centrelink

If you have questions about hep C, it's well worth a visit: www.hspace.org.au



ARE YOU GOING ON HOLIDAYS?

HAVE YOU ARRANGED A SUPPLY OF CLOTHING FACTOR TO TAKE WITH YOU?

Don't forget if you're flying interstate or overseas, you need to take documentation with you about your treatment needs and the product and equipment you are carrying. Talk to your Haemophilia Centre health professional or HFA if you need any information about this.

WORD FIND - WHAT TO DO THESE SUMMER HOLIDAYS!

AQUARIUM
PICNIC
FISHING

CRAFTS
BAKE
MUSEUM

GAMESPLAY
FAMILY MOVIES
SPORTS

SWIM
RIDE
CAMPING

FRIENDS
BEACH
ZOO

A	Q	U	A	R	I	U	M	Q	Z	E	R	M
T	S	T	R	O	P	S	K	L	O	K	B	O
B	N	M	R	I	D	E	C	U	O	F	G	V
F	R	I	S	W	I	M	A	Q	U	A	R	I
Q	B	E	A	C	H	A	B	A	B	K	S	E
P	F	I	S	H	I	G	C	R	A	F	T	S
I	M	O	V	I	N	P	L	S	K	W	I	M
C	C	A	M	I	T	Y	A	H	E	P	O	F
N	G	S	H	F	U	N	M	U	S	E	U	M
I	B	S	D	N	E	I	R	F	A	E	R	N
C	I	C	A	M	P	I	N	G	P	L	A	Y
F	G	D	R	E	B	N	F	A	M	I	L	Y

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