the H FACTOR

Issue 43

Winter 2015

Newsletter of Haemophilia Foundation Queensland

From the President

Hello everyone, remember 1-3 October is the 17th Australian & New Zealand Haemophilia & related bleeding disorders conference – see you there.

This month I want to reinforce the clear need for rest after a bleed, many of us treat and move on with life without giving the affected bleed time to heal. We may consider the bleed all sorted but tissues damaged has occurred and to get the best recovery and minimise further damage, rest is an important aspect of treatment. Doctors and Physiotherapists know form first-hand experience that better outcomes are achieved when rest is included as part of the treatment plan – just give it time, rest helps stop re-bleeding (including small micro-bleeds that can be undetected) from occurring and also ensures that a joint is less likely to have permanent damage. There is evidence to show that walking on or using a blood filled joint can severely increase damage to cartilage.

When a bleed is occurring there is often frustration in trying to rest, we all know that feeling. Sometimes it's difficult to avoid using a joint that is bleeding and can often lead to time off school or work to recover. It is clear from my experience that rest helps, take wrists as an example – try using the other hand and with a little practice it's amazing how you adapt even to the point of being able to use either hand to self-infuse factor which has helped me on many occasions.

An important point to note here is

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Inside this issue:

Presidents Message *Continued...*

that medical advice I have been given does not recommend ambidextrous training for children aged 7 years or under. Up to this age children's developing brains need to first acquire initial fine motor control as well as language and writing skills without adding further complications.

So talk to your treatment centre about your treatment plan, it's as easy as picking up the phone for a chat or making an appointment for a review – we all want to avoid progressive joint damage!

David Stephenson

President HFQ …..Advocacy, Education, Health promotion, Support

A message from the QHC team at Lady C

Many of you will know there are still some issues being resolved with the systems at Lady Cilento Childrens Hospital.

Many of these are about he hospital itself and nothing to do with your HTC team.

The following are suggestions for when and how best to coitact thye paediatric team at LCCH.

Please call the LCCH HTC
When you:

- are worried about a possible bleed
- are worried about an injury
- have treated a bleed at home
- are taking your child to the hospital

Please email or text the LCCH HTC
For queries about:

- supplies
- pharmacy
- upcoming procedures
- school plans
- travel letters
- general bleeding disorder

questions.

How to make or change appointments at LCCH

- Phone the call centre - 1300 762 831
- You will need a current referral to the consultant (Dr Simon Brown)

As much as we would like to assist you in this matter, the HTC staff are unable to access the systems for booking appointments.

Sorry.

ABOUT HFQ

The Haemophilia Foundation of Queensland (HFQ) provides advocacy, education and support for people in Queensland affected by inherited bleeding disorders. The Foundation employs a part time manager and is guided by a Board of Directors which meets monthly.

We can be contacted on mobile 0419 706 056; or via post at PO Box 122 Fortitude valley, Qld 4006

Members of HFQ are entitled to benefits, including subsidies on:

- **Medic Alert bracelets (50% discount)**
- **Electric Shavers (up to $75 off)**
- **Supportive footwear (75% off)**
- **Discounted Movie Tickets**

HFQ Management Committee

President	... ...	Mr David Stephenson
Vice President	...	Mr Adam Lish
Secretary	... ...	Mrs Leanne Stephenson
Treasurer	... ...	Mr Peter David
Members	... ...	Mr Craig Bardsley
		Mr Robert Weatherall
		Mrs Sarah Hartley
		Dr John Rowell
		Mr Erl Roberts

HFQ Delegates to HFA

Mr Adam Lish & Mr David Stephenson

Acknowledgements

HFQ is grateful for the support of our patron: His Excellency the Honourable Paul de Jersey AC .

HFQ programs and services are funded by the Queensland Government.

Internet

Find us on the web at *www.hfq.org.au* or at our Facebook page at *www.facebook.com/HFQLD*

QUEENSLAND HAEMOPHILIA

CHILDREN'S CLINIC

PAEDIATRIC CLINIC STAFF (LCCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown — Haematologist

Haemophilia Registrar Dr Melanie Jackson

Joanna McCosker – Clinical Nurse Consultant

Wendy Poulsen — Physiotherapist

Moana Harlen — Senior Psychologist

Contacting the Clinic ***Please call the mobile for urgent enquiries (during office hours only).*** *For all non-clinical/non-urgent enquires please email LCCH-Haemophilia@health.qld.gov.au*

After hours—call switch and ask to speak with on-call haematology consultant or present to the emergency department

Appointments — Contact the Administration Officer for Haematology or 2e outpatients for queries regarding clinic appointments

Haemophilia Outpatient Clinic — Dr Simon Brown — held in 2e outpatients Level 2, Thursday afternoons 1.30 – 3.30pm

Contact the Administration Officer for Haematology Department

ADULTS CLINIC

ADULT CLINIC STAFF (RBWH)

Dr John Rowell — Haematologist	3646-8067
Beryl Zeissink — Clinical Nurse Consultant	3646-5727
Olivia Hollingdrake – Nurse (Part time)	3646-5727
After Hours — Page Haematologist	3646-8111
Rebecca Dalzell — Physiotherapist	3646-8135
Michael Hockey — Physiotherapist	3646-8135
Maureen Spilsbury — Advanced Social Worker (Mon-Thur)	3646-8769
Desdemona (Mona) Chong – Advanced Psychologist (Fridays)	

Contacting the Clinic ***Please telephone in the first instance.***

Appointments 3646-7752 or 3646-7751 or speak to Beryl

Haemophilia and Genetic Clinic — Dr John Rowell — Wednesdays 1.30pm

Haemophilia/Orthopaedic Clinic — Dr John Rowell and Dr Brett Halliday — 9am every four weeks

OUTREACH CLINICS

Gold Coast Hospital *(9 Oct –Adults)*, **Toowoomba General Hospital** (14 May), **Nambour Hospital** *(15 June)*, **Cairns Base Hospital** *(11 August)* **& Townsville Hospitals** *(10 August)*: Book through Joanna at LCCH and Beryl at RBWH

A Day for the Women

1 May 2015 was a long-awaited day for many of us. A full-day workshop was organised for women who carry the severe haemophilia gene (women carriers) to come together in a safe and confidential environment to openly share their unique experiences with one another and learn from various individuals. This long-awaited workshop was organised by the Queensland Haemophilia Centre (the Centre), together with support from the Haemophilia Foundation Queensland (HFQ) and funding from a Changing Possibilities in Haemophilia® Grant by NovoNordisk. It had been advertised through various means – the newsletter, the HFQ Facebook page, mail-outs, word-of-mouth and at clinics, with the hope of capturing as many women carriers as possible.

WHAT HAPPENED ON THAT DAY

First to arrive on-scene was actually Graham from HFQ! Armed with his multi-media props, logistics and other paraphernalia, he single-handedly set up the area to make it conducive for the day's events. His quiet labour behind-the-scenes was crucial in ensuring the smooth running of the programme. Slowly but surely, women from all over Queensland started arriving. They came from geographically diverse locations starting from Casino in Northern New South Wales all the way to Cairns in far north Queensland.

It is heartening that even a mighty storm forecast (remember that recent Friday when you took four hours to get home after work?) did not stop a group of 25 heroic women from rocking up at the Kedron-Wavell Services Club for the workshop. The strong turnout demonstrates how keen these women who carry the severe haemophilia gene were to come together in such a setting.

WORKSHOP CONTENT

We wanted the workshop to be both interactive and informative. We started with the interactive part first, with an ice-breaker and a goal-setting activity. Thereafter, women were divided into groups, according to their current life stage (i.e. women who do not yet have children, women who have children with haemophilia, and grandmothers/women of adult children who have seen the evolution of haemophilia treatment over decades).

They were given questions to facilitate small group discussions and big group sharing. An example of a question is what are the issues affecting women carriers/extended families/ partners?" This enabled participants to share ideas, perspectives and experiences with one another in an informal and respectful manner. The first part ended with the sharing of personal testimonies by four women in the audience about their unique journey with regards to relationships, family planning and raising children.

The second part was informative in nature. It consisted of presentations by invited medical experts (who also made it to the venue despite the storm!) about genetic counselling, IVF processes/options and haemophilia-related updates. While largely didactic, participants also had the opportunity to raise questions and clarify issues with the respective speakers.

FEEDBACK

Early feedback from participants has been greatly positive. Many participants came up to us privately to thank us for the workshop. They generally highlighted the value of being able to connect with other women carriers, being able to hear one another's stories and learn from one another. It was also encouraging to hear that regional participants (some had to fly) said it was time well-spent.

MAIN TAKEAWAY POINTS

It is not unreasonable to say that each of us took home different learning points, depending on who we are. The Centre has gained some insights faced by women carriers. While not exhaustive, a few of the takeaway points are listed below:

Continues on page 15 →

LifeTec Visit

LifeTec is an Aladdin's cave for those needing assistance tools and devices. Last month Bec, the RBWH physiotherapist organised a visit to LifeTec for us to see what they had to offer. LifeTec provide specialist information and advice on assistive technology. A fancy name for the thousands of useful products and devices that can help people be more independent at home, at work, or at school.

LifeTec display many of these items in their Brisbane and Townsville showrooms and have a database with many more items that are available. The group of HFQ members met with LifeTec's own occupational therapist who discovered the issues and concerns we had and then guided us around the display area to view and try the items she thought would be most useful for our members needs.

It was really surprising what was on offer, these products are far more than mobility scooters and wheelchairs for the disabled. LifeTec focus on ability not disability and they support anyone with needs to find the right tools and services for them.

From difficult to open jars, to lounge chairs that are just too comfy to get out of, LifeTec have solutions

for you. And because they are government funded, they are not trying to sell you anything. They offer advice and assistance to everyone in Queensland via visits like we did, or through phone and skype enquiries and they also provide home visits via their outreach program.

They want everyone to remain independent and they aim to make everyday tasks more achievable and more enjoyable, so everyone can continue to live in their community of choice.

If you or a family member are finding some tasks difficult, you don't need to stop doing the things you love or need to do. LifeTec probably have a solution to help you learn, work, socialise, achieve independence or simply get more out of life. So give them a try or let Mona, Maureen or myself know and we'll organise another visit. You can contact LifeTec on 1300 885 886, visit them on-line at their website www.lifetec.org.au or Facebook pages, or in person at their Newmarket & Townsville display centres.

LCCH Regional Visits

The LCCH team have a state-wide role and they try to be responsive to people with bleeding disorders across Queensland. Each year they travel to centres with clusters of patients. This year the LCCH team will be visiting;

Rockhampton - 16th June

Mackay - 17th June

Townsville - 10th August

Cairns - 11th August

Gold Coast - 8th September

Nambour - 20th October

Toowoomba - Mid November *(date to be confirmed)*

Late Breaking News

Come and have a cuppa with Joanna, Moana and Graham from the paediatric HTC team and HFQ at a venue and date to be confirmed.

Parents, children, siblings, grandparents and extended family members are welcome to come in to chat, ask questions, view / review resources, or just hang out with other families and enjoy a cuppa.

We welcome any suggestions about how this time can be made useful for families and how frequent you might like them.

We are thinking half day on a Friday, once every 2 or 3 months? Watch this space for further details.

Research Help Wanted

This important research project still needs participants. The information gathered will help everyone so if you haven't started please do so. If you started previously and some questions seemed too hard, please reconsider. You can take your time and go back as often as you need to complete the survey.

For parents of children with severe or moderate Haemophilia

The haemophilia paediatric team are seeking your assistance.

The LCCH HTC is collaborating with QUT to develop a questionnaire specifically to assess parental adjustment in parents of children with haemophilia. Having such a questionnaire would help us identify the coping strategies used by parents in order to understand how to provide support to parents with children who have haemophilia. No such questionnaire exists in Australia or internationally so this is a first.

The LCCH HTC is encouraging both mothers and fathers to participate in this important research.

If you are interested in helping out please contact the LCCH HTC on 07 3068 4180 (Moana Harlen – Haemophilia Psychologist) or by email LCCH-Haemophilia@health.qld.gov.au to receive an information sheet or go online at http://survey.qut.edu.au/f/181784/dd78 to consent and complete the survey.

QUT Ethics Approval No: HREC/14/QRCH/116

We do appreciate your time and effort.

Kind regards

LCCH HTC team J

PARTICIPATE IN RESEARCH

Information for Prospective Participants

The following research activity has been reviewed via QUT arrangements for the conduct of research involving human participation.
If you choose to participate, you will be provided with more detailed participant information, including who you can contact if you have any concerns.
Developing a questionnaire to measure parental adjustment in parents of children with haemophilia.

Research Team Contacts
Principal Researcher: Dr Esben Strodl, Director of Psychology Services at QUT Psychology and Counseling Clinic (07) 3138 8416 e.strodl@qut.edu.au
Associate Researcher: Dr Simon Brown, Haematology Department – Lady Cilento Children's Hospital (LCCH) – Queensland Health (QH) (07) 3068 8111 Simon_Brown@health.qld.gov.au

What is the purpose of the research?
The purpose of this study is to gain an understanding of the experiences of parents with children who have haemophilia. We seek to better understand the coping strategies used by parents in order to better understand how to provide support to parents with children who have haemophilia.

The research team is looking for any parent aged 18 or over with a child who has haemophilia is invited to participate in this study.

Your participation will involve completing an online survey that will take approximately 30 minutes to complete.

Participants who complete the questionnaires will be in the running for six $50 I-Tunes vouchers.

Are there any risks or benefits in taking part?
The research team does not believe there to be any risks associated with this project, other than the possibility of inconvenience or mild stress.
It is expected that this project may not benefit you directly however the study may benefit clinicians and researchers to better understand how to provide support to parents who have children with haemophilia.

What should you do next?
If you would like to participate in the study please click in the link ***http://survey.qut.edu.au/f/181784/dd78***
or contact the research team for details on the next step. You will be provided with further information to ensure that your decision and consent to participate is fully informed.

Thank You! QUT Ethics Approval Number: HREC/14/QRCH/116

QUT Queensland University of Technology
Brisbane Australia

Recording Factor Usage

Why is it necessary to record factor use?

Are your recording treatments and bleeding episodes? If so well done and thank you!

You could be doing so electronically using MyABDR or you may be using a paper diary. If you are not doing either we would really like to encourage you to do so. Perhaps it may be useful to help you understand the benefits of doing so.

Advantages

With the recording of bleeds this helps the Haemophilia Treatment Centre (HTC) identify bleed patterns which may indicate your child needs a change in treatment regimen, for example dose or frequency of treatment. A more accurate picture of bleeds will help determine the right treatment for your child When at clinic you don't have to recall bleed information such as when or where etc.

By using the My ABDR application the stocktake is done for you, which saves time.

Taking responsibility and working in partnership with your HTC to improve your care

- Helps HTCs compare their treatment outcomes and so drive improvements in the care of all individuals with bleeding disorders.
- Better outcomes for you.
- Helps Government accurately plan for future treatment needs of the community.

Disadvantages

Time to record

Introduction to Bleeding Disorders for UQ med students

Last month, as a Haemophilia Foundation of Queensland (HFQ) initiative, an educational morning was hosted by the HFQ and Queensland Haemophilia Centre – Royal Brisbane and Women's Hospital, for 2nd year medical students from the University of Queensland. 42 students, divided into 2 groups attended, with the aim of understanding how patient support agencies work.

To help achieve this goal, some preliminary education was given to the students. They were taught the basics of haemophilia and other bleeding disorders, how haemophilia is managed and the complications associated with the disorder. This was an enlightening session for the students, as it highlighted the support the HFQ gives to the community, and why it is such a vital organisation. The students expressed interest in how men with haemophilia can do their treatments at home, which is a huge advance in management, and very different to other medical models.

Another very important topic was the management of patients in the Emergency Department.

Issues that were explored included serious bleeds, their management and the importance of listening to the patient, whose experience and knowledge is a vital part of their care. The impact of haemophilia for the people and families it affects was also explored with thanks to Helen and Mike who spoke from their own experience and were able to offer comparisons of haemophilia in the past and today.

This was considered a very valuable activity by both the HFQ and the Queensland Haemophilia Centre, as it works towards preparing our doctors of the future, informing them about the importance of partnerships that exist between patients, families, hospitals and community organisations.

New Cycling Record!

Last month (May 2015) UK Cyclist, Alex Dowsett set a new world record for distance cycled in an hour. He cycled 52.97 kilometres at the Manchester Velodrome, beating Aussie rider Rohan Dennis' previous record of 52.49km.

After completing his hour Alex looked like he still had more to give as he lifted his bike over his head, which in itself is a bit of a miracle because as a child physical activity was all but outlawed for him because of his haemophilia.

Now physical activity is actively promoted for people with bleeding disorders and Alex's journey towards professional cycling began (like many of our members) with swimming, but his dad is a Touring Car competitor so he felt a need for speed.

For the attempt itself Alex began just under the Hour Record pace because going out too quickly could be fatal, but at the end of the first 15 minutes he gradually built up his speed and continued to do so over the entire hour. Alex says the first 30 minutes were easy.

After 30 kilometres he was still over eight seconds behind Dennis Rohans' pace. At the halfway point he knew that he had more left in the tank and posted a few quick times. The pain didn't show as he neared the crucial final 10 minutes where many record attempts fail, a huge roar ripped through the velodrome when, with nine minutes of racing remaining, Alex rode quicker than Dennis' Hour Record pace, finally setting a distance of 52.937km.

But he reckons without the whole crowd cheering him on it wouldn't have happened. He also reckons without the factor that he takes by prophylaxis it would never have happened.

The words "synthetic medication" have sinister overtones in the context of professional cycling.

But for Alex Dowsett - and all fellow haemophilia sufferers - his regular injection will be performance-enabling rather than performance-enhancing.

A subtle - and powerful - difference.

Alex can only compete as a professional cyclist at the top level because of this. He says it's his way of life, but it can cause concern in the cycling community where drug use has been endemic in the past. Unlike generations before him however Commonwealth time-trial champion Alex Dowsett always starts his races with his blood enhanced, but his conscience clear.

As a child Alex received warnings of a possible future spent in wheelchairs and some doctors recommended he take up chess or a musical instrument, but he chose professional cycling for a career instead, with sports cars as a hobby. Alex has had his fair share of tumbles. But they are treated with the same two-fingered salute he gave the nay-saying, board-game pushing doctors of his youth. Alex says that over his cycling career he has broken his shoulder blade, collarbone, elbow and two ribs and despite some doctors telling him as a kid that if I broke a bone I'd be in hospital for months, he says he was out of hospital within a week with all of them.

Having haemophilia has contributed to some interesting incidents in the past. When he was riding for Team Sky (2011-12) they didn't actually warn any of the riders that he was a haemophiliac and what that would involve and one of his team-mates walked in when they were at the Tour of Qatar one year and said, 'Alex what the hell are you doing?' He had to explain it to him very quickly.

Alex had originally intended to attempt earlier but in the build up to the event he crashed while training out on the road and suffered a broken collarbone. During this downtime Alex travelled around Europe with the 'Miles for Haemophilia campaign', he said that on these trips he saw his story spreading hope: their boy or girl could in other people and achieve one of his own personal career ambitions though this world record attempt.

Based on an article by Tom Reynolds BBC Sport http://www.bbc.com/sport/0/get-inspired/32434988

Talking About von Willebrand Disease (VWD)

I was diagnosed with von Willebrand Disease (VWD) around nine years ago, along with my now 16 year old daughter Star. When I talk about my bleeding disorder people say “You don’t look sick at all.”

Our journey with this bleeding disorder started a few weeks after my daughter was born. In the middle of the day she started to nosebleed. Alarmed at the sight of blood gushing from the nose of our infant girl, we rushed her to the hospital emergency room.

Star was born with burses all over her body, which we mistakenly though, were merely “birth marks”, unknown to us, bruising was already a sign of the condition. It took several years and countless doctor hopping and tests before Star’s frequent nosebleeds and bruises finally got a name to it.

The diagnoses of von Willebrand Disease by my haematologist-oncologist, still echo in my mind. Suddenly everything made sense. I have always been anaemic since childhood. When my period started, it came heavily every monthly that I would sometimes have to lie down and I grew up thinking that heavy monthly periods were “normal” for me.

Despite the discomfort of my monthly periods I was never considered a candidate for a bleeding disorder. “Bleeding is for boys,” one GP told me when I raised the possibility that my daughter could have a bleeding disorder.

Mothers who carry the haemophilia gene pass it on to their sons not daughters and the affected son the n passes the gene on to his daughter, who is a carrier but can also have symptoms, but VWB is an equal opportunity bleeding disorder and affects males and females equally but it was overlooked by the doctors.

Many women with bleeding disorders are disadvantaged like myself because aside from suffering general bleeding symptoms, they also suffer gynaecological problems. Aside from my own chronic anaemia, women like me are also at risk during pregnancy and childbirth. In my experience all me three children were born pre-term and I suffered bleeds and premature labour, forcing me to take extra time off work and having period of bed rest from the third month.

von Willebrand Disease is not as difficult to manage as classical haemophilia and while the quality of life for people with VWB are not frequently impacted by bleeds we still need to be careful if we want to live as normal as possible. As a parent I tended to be over protective of my daughter but with the diagnoses she doesn’t have to live in a bubble. Like many other medical conditions, we need to manage it on her terms and not allow if to rule our lives.

Edited for size from an article by Andrea Trinidad http://www.interaksyon.com/article/106475/her-story--how-a-mother-deals-with-her-own-her-daughters-and-other-peoples-hemophilia

VWD Total Ankle Replacement

von Willebrand disease (VWD) is a recognized cause of secondary ankle osteoarthritis (OA). Few studies have examined orthopaedic complications and outcomes in VWD patients treated for end-stage ankle OA with total ankle replacement (TAR). To evaluate the mid-term outcome in VWD patients treated with TAR. Eighteen patients with VWD aged 34 – 69 were treated for end-stage ankle OA with TAR. After an average of 7.5 years the complications were recorded. Component stability was assessed with weight-bearing radiographs. Clinical evaluation included range of motion (ROM) tests and under fluoroscopy. Clinical outcomes were analysed by a visual analogue scale, and a Health Quality of Life (QOL) Survey.

One patient sustained an intra-operative medial malleolar fracture. In two patients delayed wound healing was observed. Two secondary major surgeries were performed. Pain level decreased from 8.2 preoperatively to 1.1 postoperatively. Significant functional improvement including ROM was observed. All categories of the QOL score showed significant improvement. Mid-term results of TAR in patients with VWD are encouraging. The total rate of intra-operative and postoperative complications was 33.3%. However, longer term outcomes are necessary to fully understand the clinical benefit of TAR in patients with VWD.

Source: http://onlinelibrary.wiley.com

Aspiration stops joint damage

Researchers in Western Australia studied hospital records of boys under 16 years of age with severe haemophilia A. Patients were examined every 3 months by a haematologist, a paediatric rheumatologist, a paediatric physiotherapist, a haemophilia nurse and a haemophilia social worker in a multidisciplinary outpatient setting.

Of the 46 boys studied, 22 required joint washouts to avoid joint damage during the 11-year study period, with a similar protocol followed for each patient. In total, 84 procedures were performed during the study period. Aspiration was performed as soon as possible after a bleed. Examination was performed to confirm haemarthrosis and rule out other conditions.

Saline was injected incrementally until the fluid removed was clear. Corticosteroids were injected into the joint after the procedure, and factor was administered at the start and the next morning to avoid additional bleeding.

Of the 84 joint bleeds, no infections or extra-intra-articular bleeding occurred as a result of the washout procedures, and joint rupture did not occur. No other side effects from the procedures were observed during the 11-year study period.

Of the 22 boys who underwent the washout procedure, 15 had clinically normal joints during follow-up. Seven children with joint damage either had damage documented prior to the procedure or did not have complete removal of hemarthrosis during the procedure, the researchers reported.

Edited for size from: Manners PJ, et al. J Rheumatol. 2015;doi:10.3899/jrheum.141236.

Haemophilia Word Find

Can you find 18 words relating to haemophilia and bleeding disorders in this table? Words like **ADVOCACY**. Other words top look for are: EDUCATION; INHIBITORS; BLEED; FACTORS; JOINTS; BLOOD; HAEMOPHILIA; BODY; PROPHYLAXIS; HEALTHY; RESEARCH; CARRIERS; HEREDITARY; SWIMMING; CLOTTING; INFUSIONS; and VONWILLEBRAND

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

Weird Science

Sometimes the days can go really slow, but if you want to fill some time and explore the world around you that's doing science! It's about observing, experiments and figuring things out.

You won't be bored if you do your own experiments but be sure to tell mum or dad before you try these ones. All you need is things like baking powder, lemons, a magnet, balloons and a straw ~ no fancy chemistry sets needed.

The straw rocket blaster

You need string, some tape, a drinking straw, and a balloon. Take one end of the string and tie it to something solid and fixed, like a chair or a door handle. Thread the other end of the string through your straw and tie it to another chair or handle at least four metres away. Make sure the string is taut.

Now blow up the balloon, keeping the opening closed with your finger. Tape the straw to the balloon and slide the blown-up balloon along the string until the opening of the balloon is at one end and the rounded part faces the long line of string. When you let the air out of the balloon, it will shoot like a rocket along the line of string to the other end.

How long can the sting be for the balloon to still make it the entire length?

Tie the string up a staircase or to a tree limb outside to see if it will make it to the top;

You can tape weights to the balloon to make your rocket carry a pay load. How much weight will it take to stop it taking off?

For more of a mess you could try **the baking soda and vinegar volcano** but please do it outside.

Most kids have made coke volcano using Soda and Mentos. It's is a real science experiment that doubles as a great excuse to make an explosive mess (it can produce eruptions of up to 6 metres high if done correctly) but if you don't have Mentos you can do a similar experiment with baking soda and vinegar which is a bit less messy and you can even put a timer in it. How?

Combine 1/4 cup of vinegar and two drops of dishwashing liquid (the soap in the soda breaks the surface tension, making a bigger volcano) in a tall glass or beaker, then wrap the baking soda in toilet paper, put a string around it and drop it into the beaker. Now you've got a little extra time before the vinegar eats away at the toilet paper and gets the baking soda wet. It's kind of a timed explosion for your volcano.

For extra colour add food colouring to the vinegar. Don't use baking powder, as this contains inert ingredients like cornstarch that will dampen the effect.

The lemon-powered clock

For this, you need galvanized nails, a couple of copper 1 or 2c pieces, some copper wire, and a juicy lemon. Stick a nail into one side of the lemon and a copper coin into the opposite side (you may need to cut a small slit into the peel first). These are now natural battery terminals.

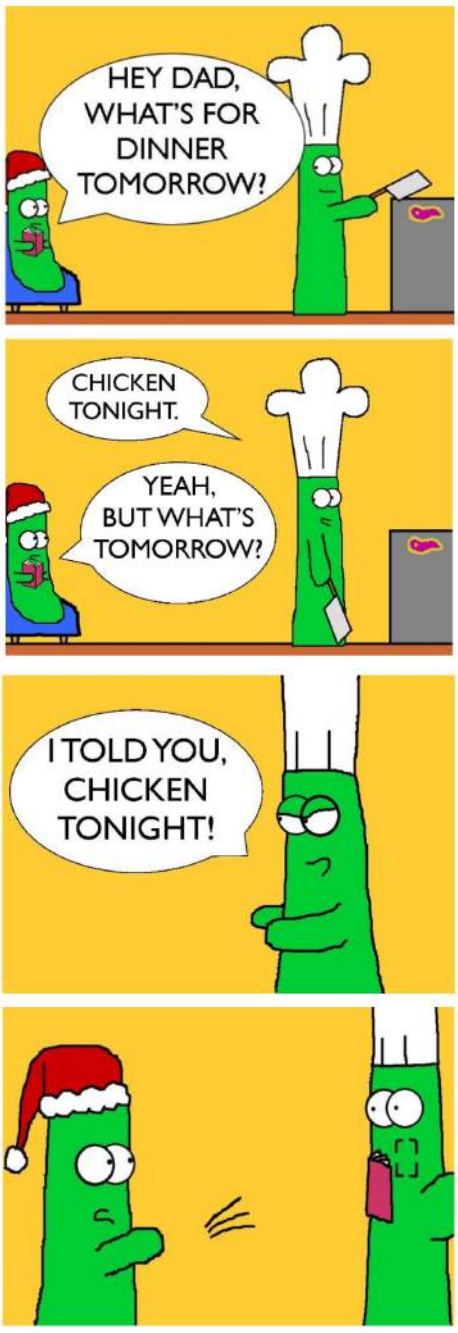
Attach the ends of these wires to the correct terminals of a small battery-powered clock and you may have enough voltage to power it. If not, use two or more lemons, putting a nail in one and a penny in the other, connected with additional copper wire. This will increase the voltage. In fact, the more lemons you link together the more power you will get.

Why? Galvanized nails are covered with zinc. The zinc atoms are drawn toward the copper, creating an electron flow through the lemon from the nail to the coin. Now tie copper wire to the coin and another to the nail, leaving the ends free.

The Slobs

by Conor Birkett

First published by the Irish Haemophilia Society.
http://www.haemophilia.ie/content.php?id=7&article_id=698&level3_id=860



Haemophilia A Inhibitors & Mortality

A new study called "Impact of Inhibitors on Haemophilia A Mortality in the United States," was published January this year in the American Journal of Haematology. The study included over 7,000 males with severe haemophilia A. Patient data for the study covered a 13-year period and in that time 432 participants died; of those, 48 had an inhibitor.

Primary findings were as follows:
Males with severe haemophilia A who have an inhibitor are at increased risk of death.
Males with an inhibitor were 70% more likely to die compared to those without an inhibitor, even when other risks for death, such as older age, liver disease and infection with either HIV (the virus that causes AIDS) or hepatitis C virus, were taken into account.
Of the 48 patients with an inhibitor who died, 42% had a haemophilia-related cause of death (due to a bleeding complication) vs. only 12% of patients without an inhibitor who died of a bleeding-related complication.

Additional surveillance data is needed an inhibitor prevention strategy can be developed. The results of this testing will be used to determine the number of people with inhibitors in the US haemophilia population and collect information about when they occur. Routine screening through the QHC's may help uncover an inhibitor early in its development when treatment to eliminate it is more likely to be successful."
Source: CDC, March 24, 2015

- See more at: http://www.hemophilia.org/Newsroom/Medical-News/CDC-Study-Looks-at-Correlation-Between-Hemophilia-A-Inhibitors-and-Mortality?tr=y&auid=15541702#sthash.2PKGdijt.dpuf

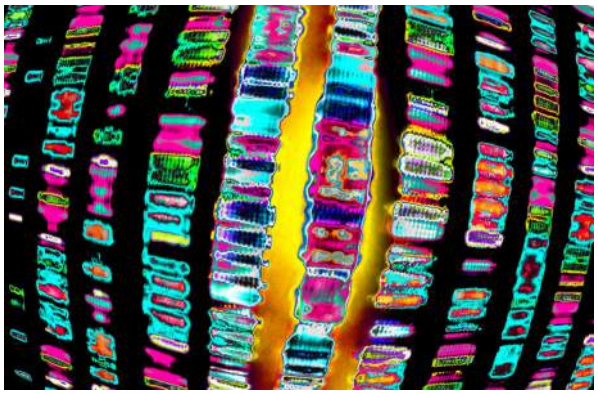
Gene Therapy Gets Closer

For many years, researchers have been investigating the use of gene therapy as an alternative treatment option for patients with haemophilia. One gene therapy strategy that has shown some promise involves injecting patients with vectors. However early trials of this technique have raised concerns because the higher the vector dose, the stronger the immune response.

As a result researchers set out to find a technique that delivers lower vector doses to reduce immune response, while effectively producing clotting factors.

Chief researcher Dr. Arruda and colleagues found that an Italian man with thrombosis (excessive clotting in the blood vessels) had his condition triggered by a mutation in a factor IX (FIX) gene. This gene - which they named FIX-Padua after the Italian man's home city - was the opposite to all previously identified FIX mutations that cause haemophilia. Its ability to clot blood is 8-12 times stronger than normal FIX genes, making it a potential candidate for gene therapy in patients with haemophilia.

FIX-Padua was administered via injection to three dogs who had severe forms of haemophilia B similar to those found in humans.



The two dogs had no prior inhibitory antibodies and showed significant improvement in their haemophilia within 1 week, easing from severe to mild. In addition, the dogs had no bleeding episodes for up to 2 years and they had no immune response to FIX-Padua, nor was their any sign of thrombosis.

The third dog had pre-existing inhibitory antibodies and also showed significant improvement following treatment. The animal's haemophilia eased from severe to mild, and this persisted for up to 3 years. What is more, the inhibitory antibodies that the dog already possessed were eradicated - something the researchers say has never been seen in an animal model before.

The team also tested FIX-Padua in mouse models of haemophilia and found it produced similar results.

Dr. Arruda says the findings may provide a new approach to gene therapy for haemophilia and perhaps other genetic diseases that have similar complications from inhibiting antibodies. A clinical trial is already underway in the US testing the safety and efficacy of the FIX-Padua gene therapy in adult patients with haemophilia B.

Edited for size from an article by Honor Whiteman
http://www.medicalnewstoday.com/articles/290891.php

Making the most of Clinic Appointments

Preparing for any appointment with any doctor can be a cause of stress. Knowing you are prepared for your appointment can help reduce stress and also make sure you get the most from your QHC visit. The appointment should be a time for you to receive answers to any questions or concerns you may have and to clarify any treatment plans you are asked to follow.

QHC Appointments

Don't be afraid to participate, and take an active role in your care. One of the best ways you can do this is to provide the team with as much information as possible regarding any symptoms or health incidences since your last visit.

Other Doctors

Any medications prescribed at the clinic will be in their records, but they may not know what other medications & treatments you are one and these can have an impact on your health outcomes. Many people use alternative therapies and it's useful for them to know about these as well as your other medications so they can avoid unintended or harmful interactions. Also take a record of any visits to other health care professionals, your local GP, physiotherapist, psychologist etc as well as chiropractors, naturopaths, or other practitioners.

Recording incidents and treatment progress

It's good to document your symptoms and treatment progress. These records help the clinical team understand how well your treatments are working and to identify any patterns when bleeds occur or other symptoms appear. It also helps the Aus Blood people know what amount of blood products you use and what type, so they can plan for future years and organise for enough to be available in Australia.

This can be done by using the MyADBR app, journal or website; or you can create your own journal. This is vitally important because the symptoms of everyone's bleeding disorder is different. At the onset of a bleed and other symptoms, you should write down a description of your experience. All patients should be active in recording their health not just people with bleeding disorders.

If you're not using MyABDR or the event is health related but not bleed related, bringing any notes with you as it can help remind you, and allows for your doctor better understand what's going on & how your symptoms affect your daily life.

Questions from the Doctor

All doctors ask questions to try & pinpoint your symptoms and review if changes are needed in your treatment program or a new treatment is required. This is true of GP's and Haemophilia specialists. With haemophilia one of the primary goals is to determine if there is a specific event or incident that could have caused a bleed to occur. A secondary goal is to confirm that the level of factor currently prescribed is working for you.

Questions for the Doctor

Time is limited during clinic visits. Prepare for your appointment by thinking about what you want to do during your visit. Do you want to:

- Talk about a health problem?
- Get or change a medicine?
- Get medical tests?
- Talk about surgery or treatment options?

Write down your questions to bring to your appointment. The answers can help you make better decisions, get good care, and feel better about your health care.

Bring paper and a pen (or a Smartphone)
It helps to write down things that don't make sense, and ask for

Continues on page 15 →

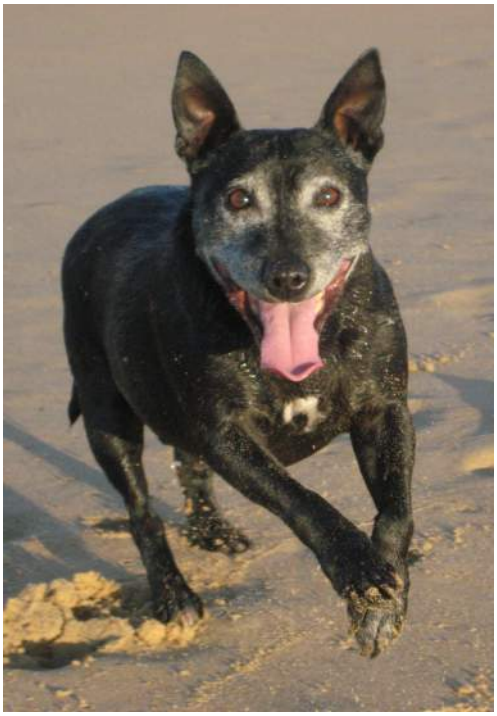
5 Ways to Avoid a Mid-Life Crises

The expectations of masculinity have been shifting and some men are struggling to live up to the impossible standard of being an 'alpha male': having a good career, good marriage, a couple of good kids, earning a lot of money and retiring well. With that sort of pressure, it's very easy to feel like you're doing something wrong or have failed. It's no wonder the suicide rate amongst men is at its highest since 2001 and the age group most affected are those aged between 45 and 59. This feeling and this pressure creates the true midlife crisis but it can be avoided or minimised.

1. Help somebody worse off than you Reconnect with your own sense of wellbeing and purpose by helping somebody worse off than you It may seem like the last thing a person in crisis needs, but if you're stuck not knowing what to do, helping people who perhaps have more serious problems than their career falling on hard times or suffering from unhappiness at home can be enormously fulfilling.

2. Open up It is an ancient cliché, but even in the modern age where we have more methods of communication than ever, most men remain just as unwilling as ever to articulate their emotions. Fraser says that learning to verbalise and share our doubts, worries and insecurities is often the first step towards solving them. And it needn't be as difficult as you imagine. Start one-to-one with the right person, rather than to a group in the pub. Let your friend know you value his or her opinion and that you want to ask them something," he says. "It needn't be formal or dramatic, but you might be surprised by the results."

3. Remember: your career is pointless Most men tend to define themselves by what they have achieved in work, because that is what they are told is important. But jobs come and go and in the end we tend to fade out rather than finish when we want to. Ultimately you career is pointless," Fraser says. "Even if you do everything you ever wanted to in work and reach the top of your field, you still eventually fall off the top of it. More likely you fall off somewhere in the middle, though, at your peak. At some point there will be a crash, so you must ask yourself: what difference do you want to make?" Fraser points to a quotation by the late Labour Party grandee Tony Benn: "The people



who have sacrificed their view in order to get to the top have very often left no footprints in the sands of time", and argues that signing your life over to be a "wage slave" to a corporate employer generally means working on somebody else's plan, while ignoring your own needs. No matter how much you earn, your real wealth may not lie in your pocket," he says.

4. Tell yourself a better story With the news full of horror and misery, learning to filter can be imperative to maintaining a positive outlook on life. Relentless spools of misfortune in the headlines can be wearying, and television news is the worst culprit. With newspapers you have a choice to read which sections you like, and choose what you feel is relevant," Fraser says. "In front of the TV, you're at the whim of the producer, so it's the persistent list of negative stories interspersed with adverts that make you feel awful. If you begin to filter that 'consumer' narrative, everything can change. I call it telling yourself a better story – you can pick and choose what messages you receive." It doesn't stop at news. Social media can also be harmful, especially if you see an endless stream of gloating Facebook posts and self-congratulatory LinkedIn updates: evidence has suggested that there is a link between high Facebook activity and depression. "You can choose what you pay attention to," Fraser says. "So choose what makes you happy." Tempting as it can be to revert to old habits, it's not always a good idea.

5. Listen to your elders For men who experience a crisis of identity in middle age, there is a tendency to reconnect with their youth, be it via a new pair of high-top trainers or letting loose in a way they likely gave up years ago. While Fraser says that's not wholly unhelpful, more important is looking in the other generational direction, towards elders who know what it's like to deal with the challenges of ageing. "Listening to wise heads can save us a lot of grief," he says. "Generally as a society we don't put enough value on learning from the old: those who've been there and done it. The emphasis is always on the latest answers and treatment, but most of those stem from ideas that are decades old. For all the therapy in the world, watching It's a Wonderful Life is the perfect guide for a mid-life crisis."

Dr. David Fraser

Published in e-male Issue 146 May 2015

Clinic Appointments *Continued...*

clarification. If there are words that you've never heard of, ask your doctor to spell them. Make sure you record & understand your plan. You could use time between appointments to look up what your doctor has told you. The smartphone can help keep you busy if your wait is long!

Bring your Medicare card, if required. It sounds a bit silly, the clinic tam already know who you are, but some treatments and procedures require you to prove your Medicare entitlement and it avoids delays if a new treatment or procedure has to be undertaken. Cards also have expiry dates and the public health system is required to collect this information from you.

If you think you need moral support or a back-up for a poor memory, bring someone with you. They will give you support during the appointment and they can help remind you of your questions and concerns.

Having someone with you can take a lot of pressure off, especially if you're facing bad news, a complicated diagnosis, or even if you just get flustered around doctors. Whether it's your partner, a family member, or a trusted friend, they can offer support as well as a second set of eyes and ears.

After Your Visit

Be sure to follow any directions you were given for treatments of scheduling other appointments, referrals, or tests required. Failing to follow up on these or any day-to-day recommendations could have an negate and improvements in your health.

Medical conversations can get complicated. There is a lot of information being exchanged. You have to talk about what's going on, remember when things started, think about environmental cues. If you don't think you understood any answers or advice you get relating to bleeding disorders you can also ask the HFQ staff to help you further understand the information you have been given.

Woman's Forum *Continued...*

Women carriers are the main advocates for their children with haemophilia and their needs change as they reach different milestones of their journey.
Women carriers in regional areas do struggle more and will require more resources and support.
Mothers need more guidelines on carrier status testing for their daughters.
It is important to include other children, partners and extended families in education and support programmes
Networking opportunities are highly-valued by women carriers and women carriers are keen to support one another.
Different people cope differently and there are some factors which are protective and make it easier.

WHAT'S NEXT?

Further collaboration between the Centre and HFQ
As a big group, participants had the opportunity to discuss what sort of support/programmes they would like to have from the Centre and HFQ. Target areas (e.g. support for partners of women carriers) were identified and some creative ideas were also generated through the discussion. Some spoke about the need for emotional support, respite support and even networking opportunities for children to get to know one another.

Networking among women carriers

To our knowledge, there are a few Facebook groups which have been launched by individuals to help connect parents/women carriers. Some participants have also said they are happy for their contact details to be passed on to other women carriers. So, if you are needing more information/ support, you can contact the Centre or HFQ.

Keep the conversation going
Even if you did not attend the workshop, you can approach the psychosocial workers at the Centre or to make contact with the HFQ proactively, if you wish to contribute to this discussion.

This workshop is the first step in the right direction in providing a sustainable service to women carriers. There is much work to be done and we are optimistic that together with the women carriers who have spoken, we would be able to develop more meaningful services for this community.

Finally, we would like to applaud the bravery of our women participants who openly shared their stories and experiences with other women in the group. Without your active participation and openness, the workshop would not have achieved its purpose. Thank you.

PBAC Decision ~ New hepatitis C Drugs

PBAC has recommended the following hepatitis C treatments be added to the Pharmaceutical Benefits Scheme (PBS):

- Daclatasvir (Daklinza®) in combination with Sofosbuvir (Sovaldi®)
- Ledipasvir with sofosbuvir (Harvoni®)
- Sofosbuvir (Sovaldi®)

PBAC stated that "new treatments for HCV were very effective" and would offer options for treating people with genotypes 1 to 6.

PBAC also recommended that these oral treatments should be listed in the General Schedule, meaning that prescribing would no longer be limited to specialist clinics.

However, PBAC was not satisfied with the proposed prices and advised the Health Minister to negotiate lower prices for them.

NEXT STEPS

Gavin Finkelstein, HFA President, said that Government funding is needed urgently for these medicines to be listed on the PBS so they are affordable.

The next step in the process is for the Australian government to consider the recommendations because access to these medicines is critical.

"GAME CHANGERS"

These new treatments are part of the new wave of Direct Acting Antiviral (DAA) drugs that are far more effective against hepatitis C than the previous treatments. Most of these treatments are already available in other countries.

In clinical trials they have had very high success rates (some over 90%) with few side-effects, and shorter treatment courses. Some need to be taken in combination with other medications to be effective. But some will be available in interferon or ribavirin-free combinations. There have been encouraging results even with people who previously had unsuccessful treatment or who have advanced liver disease.

AND IF YOU HAVE HEP C?

If you have hepatitis C and a bleeding disorder, remember that you need to have your liver health assessed before you can be considered for treatment:

- Make sure you have your liver health checked regularly
- If you don't know where to start, talk to your Haemophilia Centre
- Stay in touch with your hepatitis clinic about what's new
- Go to your appointment with the hepatitis clinic after your liver health check, even if the fibroscan shows your liver health is stable

And let your Haemophilia Centre know about your liver test results or how your treatment is going to make sure they stay in the loop.

From: HFA E-News, Special Hep C edition

The Aus & NZ Conference is *OUR* conference

The 17th Haemophilia and Related Bleeding Disorders is on the Gold Coast this year. The theme for the conference is "Facing the Future Together". We are looking forward to a good HFQ presence at this Conference where we will discuss and debate issues and follow up on ideas and connections made.

If you would like information on the conference please go to the conference website. HFQ is keen to assist members to attend and we would like to see a representation of members from across Queensland and also representing the various elements of our community (affected and infected individuals, all conditions etc.) so if you want help from HFQ to attend then please download our Scholarship Application form from the website and send it to us ASAP. If you need any other assistance, please contact Graham at the HFQ office (07) 30171778 or mobile 0419 706 056.

Membership Renewal

HFQ membership subscriptions are due for renewal. The side of this page can be torn off and used as your 2015-2016 Haemophilia Foundation Queensland (HFQ) membership form.

HFQ is not like life insurance. IT is not a union, nor a church or a school; but we are a community of people dealing with the issue of living with a bleeding disorder. We are a registered group that through our financial members can prove that we represent people with bleeding disorders in Queensland.

Through the HFQ board and subcommittees we advocate for improved services and programs on your behalf and we provide direct programs and activities where you have made the need for these apparent to us.

We only have one part time staff member so your fees are important to us. Over the past 12 months HFQ has continued to provide services to the bleeding disorders community in Queensland and we rely on your support in the form of membership to maintain these services.

Limited funding from Qld Health provides financial support which goes some way to allow us to deliver outcomes for our community, however government funding is not dependable and our current funding will run out in 2017. A number of activities that we do require us to raise money elsewhere and independently of Qld Health.

Community Camp, regional support activities, youth camp & mentoring activities, health & wellbeing seminars, welfare support for those in need, and a range of targeted services in partnership with the Queensland haemophilia centre addressing community needs could not be achieved on Qld Health money alone.

Having a membership base allows us to demonstrate we represent the bleeding disorders community and the fees you pay help make up the shortfall in the programs we currently provide.

We rely on fundraising to ensure these services happen and I thank those who donate to us or volunteer their time at events like Bunning's BBQ's and the like.

A significant part of fund raising is membership subscriptions and this is one easy way you can help HFQ help those in need in the bleeding community.

Please complete the attached membership form. HFQ looks forward to your continued support and thanks you for your subscription.

We recognise that the small annual fee can still be too much for some people so we also have provision for accepting members in financial distress so that you still remain part of our organisation. Please talk to Graham if you are in this situation

Regards,

David Stephenson

President HFQ ….. Advocacy, Health promotion, Education, Support

HFQ MEMBERSHIP RENEWAL TIME

Please tTear off this section and fill out the details on the reverse to renew your membership

Membership of HFQ for 2015/16 is $20 per annum for each membership or $100 for a lifetime membership. These fees are due at 1 July each year and membership is open to all people with a bleeding condition, their families and people wanting to support a person with a bleeding condition.

Please fill out this form, tear if off and return to HFQ at PO Box 122 Fortitude Valley Qld 4006

Name: _____

Address: _____

Phone No: _____ **Email:** _____

Membership: ☐ Annual ($20) or ☐ one-off payment ($100) **Donation : $** _____ **Total: $** _____

HFQ does not share information on members with the exception of Haemophilia Foundation Australia where joining HFQ automatically entitles you to access HFA services and programs and to receive National Haemophilia and supporter mail free.

☐ **Please mark this box if you do not want you details recorded on the HFA data base.**

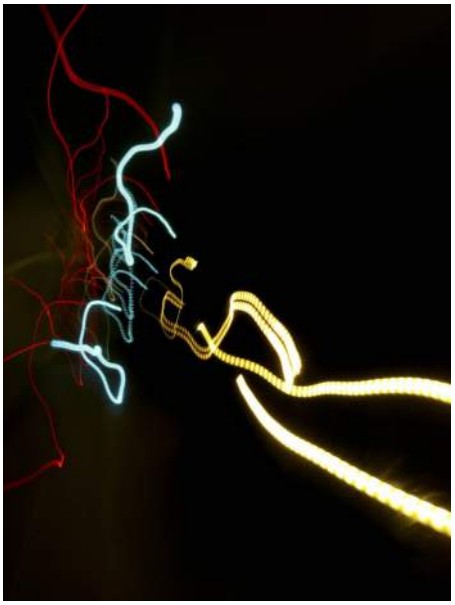
Good Viral News

A new therapy using antibodies in HIV patients was shown to reduce the presence of HIV up to 300 times. The study was the first in humans after previous research showed success in mice and nonhuman primates.

Dr. Barry Zingman, medical director of the AIDS Center and clinical director of Infectious Diseases at Montefiore Medical Center and a collaborator on the study said the findings of this study are very significant in that it is the first proof of concepts that an antibody-based therapy could be effective in controlling HIV infection. This new type of therapy could be used to replace or supplement standard drugs.

The antibody treatment was injected in a range of concentrations in 12 negative and 17 positive patients. After 56 days, viral loads had dropped up to 300 times in eight the positive patients who received the highest dose of antibodies.

HIV is difficult to treat because it is constantly mutating and creating new strains and the immune system cannot keep up production of antibodies to fight it. The antibody the patients got, called 3BNC117, is a "broadly neutralizing" antibody produced in 10 to 30 percent of HIV positive people. It's special because they can target 195 out of 237 different HIV strains. This antibody takes years to develop naturally, and by then it it is too late to help fight the virus. However, if injected in a patient at a much earlier stage of infection, the antibody can target the virus's binding site that allows it to invade cells and replicate. By attacking the virus at this stage and at this site, the antibodies prevent the virus from replicating.



The treatment has other potential applications outlined in a Forbes article including preventing infection in people at high risk of exposure. However, it's unlikely that this treatment would prevent infection on its own and would need to be used in conjunction with other HIV treatments.

"A single neutralising antibody is unlikely to sustain HIV suppression for a long period," the study's co-lead author, Dr. Florian Klein, an assistant professor of clinical investigation at The Rockefeller University's Laboratory of Molecular Immunology said to Forbes.

"Therefore, neutralizing antibodies are most likely to be used together with other neutralizing antibodies or currently available HIV medication."

By Katie Peoples April 29 2015
http://www.hivplusmag.com/cure/2015/04/29/study-first-human-trial-shows-antibody-causes-300-times-drop-hiv-virus-blood

Health Updates

Get Moving

Getting enough exercise and eating healthy foods are important. Many studies and reports recommend that adults get 30 minutes of physical activity and that children get 60 minutes of activity per day, at least 5 days a week.

It may sound tough to fit in that much exercise most days of the week, but it's easier than you think. Try upping your heart rate during your usual daily activities. For instance, walk or bike to work instead of driving or taking the bus. Take the stairs instead of the escalator or elevator. If you're new to exercise, start slowly and work your way up to the recommended amount of activity.

Originally Published January 2015

Walking Helps Osteoarthritis.

People with osteoarthritis benefit from walking. Even 6,000 steps a day prevented subjects from developing "functional limitations"; problems getting out of bed or a chair, negotiating footpaths etc.

The steps can be accumulated during the course of the day, not all at once. Walking helps people with osteoarthritis by increasing flexibility, strengthening muscles that support joints, and improving flexibility and circulation.

Consider using a pedometer to count your daily steps. Then work your way up from 3,000 steps per day to the recommended 6,000, say the authors of the study.

Arthritis Care & Research online journal January 2015

Australian couple sue over embryo test 'failure'

An Australian couple has launched a court action after the mother gave birth to a boy instead of a girl. The couple had undergone IVF and PGD at Melbourne IVF to select female embryos for-implanting in to avoid haemophilia. Instead, the mother gave birth to a boy, Jess, who doctors later confirmed is affected by the condition.

The couple allege that they informed that the child was not a girl. If the couple had known they would have considered terminating the pregnancy. Sex selection to reduce the risk of a serious genetic condition is permitted in Victoria.

The couple love their little boy, but they tried everything to avoid this situation, and now they say their boy will have to go through pain and treatment in order to survive.

By Antony Blackburn-Starza in BioNews 450 http://www.bionews.org.uk/

Human Genome Mutation Rate

UK Scientists have worked out the mutation rate in the human genome. The team have found that it is one mutation in every 15 to 30 million letters per generation, which means each person has 100-200 new mutations in their DNA.

Haemophilia researchers previously estimated the incidence of mutations in the haemophilia gene to be a one in 50,000. The exact mutation rate - one in 30 million nucleotide in the whole genome each generation confirms previous findings

By Alison Cranage in BioNews 524 http://www.bionews.org.uk/

Sex Determination Possible at 5 Weeks.

A new test has been developed to determine the sex of an embryo from only five weeks old. The test utilises blood samples from the mother & carries no risk to the child.

The first trial used blood samples from 203 pregnant mothers verified the accuracy of the technique with 100 percent accuracy.

The test may be useful to women who carry X-linked chromosomal abnormalities. The new test reduces invasive procedures in pregnant women and can clarify inconclusive reading by ultrasound.

By Dr Rebecca Robey in BioNews 641 http://www.bionews.org.uk

HFQ Note: *With IVF, there are 2 PGD options. PGD can screen embryos to determine sex, or PGD can screen embryos to determine if they carry the haemophilia gene (regardless of sex). Accuracy rates are 96% to 98% and vary depending on the IVF clinic, so the foetus (boy or girl) still had a 2% to 4% chance of having the haemophilia gene.*

Biogen moves into gene therapy

Biogen Idec has made a deal to develop gene therapy for haemophilia A and B using lentiviral vector-based gene therapies. There is hope that gene therapy could one day lead to a single-dose, lasting therapy.

Lentiviral vector technology uses engineered viruses to insert genes into the genome of a living cell. In the case of haemophilia treatment, potential vectors will be designed to carry healthy copies of clotting protein genes into the liver cells of haemophilia patients. The hope is that this will allow the patient's body to produce the normal clotting protein, stopping the symptoms of haemophilia.

By Dr Lucy Freem in BioNews 788 http://www.bionews.org.uk

Important Dates for HFQ Members

OBE's (Old Boy's Essentially) Meets in SE Queensland on the first Wednesday of each month.

Community camp 2015 We've rebooked Noosa North Shore Retreat for 28 – 30 August 2015

17th Australia & New Zealand Haemophilia Conference 2015 Gold Coast. 1-3 October

Haemophilia Awareness Week & Red Cake Day 11 – 17 October 2015

Youth camp 2015 This is booked for 30 October – 1 November 2015. More details will be in later issues.

Please call Graham at the office on **07 3017 1778** for more info on any of these events and activities.

HFQ Annual Camps

Haemophilia Foundation Queensland has been organising and delivering camps and activities for children with haemophilia A & B as well as other bleeding disorders. Our community camps are a time when you can bring the entire family along. We keep the costs low and grants are available to make the camp affordable for everyone. Over the past 4 years HFQ has sourced more than $120,000 worth of funding to make this happen.

Children with a bleeding disorder and their families go through a rollercoaster of emotions while growing up - frustration, anger, sometimes depression and often isolation because not everyone around them understands what life is like with a bleeding disorder. A bleeding disorder diagnosis not only affects the entire family, but every part of a child's life.

While our original camp date was flooded out by cyclone X it's on again and we invite you to register you interest in attending. By running our annual camp as a low cost event, more families can attend and that enables children with bleeding disorders to meet and share their experiences with other children who are living with the same condition, while also improving their skills and knowledge in managing their bleeding disorder. Participants learn about balancing their lives through a mix of fun activities and educational exercises.

To attend this years community camp, please apply ASAP as places are limited. You can download the application form from our website or call Graham at the office.

The other annual camp we run is exclusively for young people with bleeding disorders. Most years this has meant the boys living with a bleeding disorder, but we know that siblings (including girls) also have difficulties coping so if your have children who would benefit from a weekend away at Emu Gully with lots of supervised fun activities, please let us know. Our youth camp provides your children and teenagers with a fun-filled, positive time away from home. This years camp is at the end of October and will be designed to meet the physical, social, emotional and health needs of each participant. Oh, and they're awesome fun, too!

Previous youth camp were a chance to splash-out while doing a mud run, go-fast on the buggies and climb the walls (literally — we do have rock climbing), but the boys also got to hang out, make friends, feast on great food, discuss self treating, and laugh a lot! And all of this is made possible by our amazing, accredited volunteer youth leaders who have paid their own way to join you on camp!

Interested? Check out the details on our website and talk to Graham or discuss it with the LCCH team or one of our youth mentors. Get in quick and we promise your kids the time of their life!

About The H' Factor

The 'H" Factor is published four times each year by HFQ. We occasionally send important information and updates on local and relevant events for people affected by bleeding disorders to subscribers of our email list. If you would like to be on the HFQ Email List, please register your interest by sending through an email with the subject title The 'H' Factor email list' to info@hfq.org.au. You can be removed from the list at anytime.

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