the FACTOR

Issue 41
Summer 2014

Newsletter of Haemophilia Foundation Queensland

President's Message

Pain, is it a bleed or not?

Hi again everyone, how many times do we ask ourselves or others "is this the start of a bleed or is it arthritic pain". This month I look at what people think about this.

Pain is felt when tissue is damaged but this is not always the case, it is complex with emotional and social aspects that varies between people as the brain interprets many aspects. Because of interpretation, pain it is unreliable to define, with a mix of stress, anxiety, social cultural, biological and experiences from your past all contributing to your personal pain experience.

Pain can cause functional limitations and affect quality of life. Pain in joints relate to a number of factors - obesity or excess weight, bleeding, arthritis, arthropathy and others. Warmth, swelling, loss of range of movement with pain are common to bleeding or arthritic pain.

When the pain is acute it's a danger signal that may need clotting factor - if the cause is a bleed. On the other hand if the pain is arthritic, clotting factor makes no difference. On top of this, some experience both bleeding and arthritic pain at the same time. In one study of people between 18 to 70 years, 80% reported pain but only 36% took pain medications, another study from the USA (witcop et al Haemophilia 2012) compared pain across mild, moderate & severe haemophilia and interestingly they all reported on average the same level of pain (mild 3.9/10, moderate 4.3/10 and severe 4.2/10).

So what's the difference in pain and what are some of the

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President's Message Continued...

strategies people have used:

Difference in pain

- Bleeding
  - Funny feeling
  - (Semi) acute
  - Pain increases
  - Loss of function
  - Swelling
  - Warmth
  - Intense
  - Good response CFC
- Arthritic pain
  - Chronic
  - Increase functional limitation
  - (swelling)
  - (warmth)
  - Less intense
  - Poor effect CFC

Strategies to handle pain; 764 patients 18-84 years (Witkop Haemophilia 2012)

- Acute pain
  - Factor 84%
  - Rest 81%
  - Ice 78%
  - Elevation 69%
  - Compression 65%
- Persistent pain
  - Rest 84%
  - Compression 58%
  - Ice 58%
  - Factor 58%
  - Elevation 47%

Telling the difference is difficult and some people conclude they are having a bleed when its arthropathy, if there is no arthropathy the most likely cause may be a bleed, if there is arthropathy it could be a combination of bleed and arthritis or just arthritis. It is possible to tell the difference if you have a high resolution musculoskeletal ultrasound but this is not practically available. So how often are we correct in concluding it's a bleed, there was an investigation on this (ref cerponis Haemophilia 2013) where 33 patients said they had a bleed but on investigation with ultrasound only 12 had bleeding, also 5 patients said they had arthritic pain but after the scan it was 2. So only 30% of patients had diagnosed correctly. Doctors were also given the opportunity to tell if it is a bleed or not, in this case they were a little more accurate at 45% correct diagnosis but it is clearly difficult to tell the difference between acute bleeding from arthritic pain.

So sorry to say there is no easy answer but keep in touch with your treatment centre, they are happy to talk to you on the phone and remember to make an appointment for your regular review, keep your MYABDR diary up to date as this helps everyone achieve the best treatment outcomes / plans!

I wish you all a merry Xmas and new year.

David Stephenson
President HFQ

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.

Graham Norton
HFQ Manager & The 'H' Factor editor
Ph: (07) 3338 5604 E: info@hfq.org.au

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

The Children's Hospital has Moved.

The RCH team is now located at the Lady Cilento Children's Hospital 501 Stanley Street, South Brisbane.

The main hospital number is (07)3068 1111. Please call the clinical team via this number until the direct numbers are known.

The Haemophilia mobile (0438-792-063) remains the same & can be called during work hours.

The Children's Clinic has 2 new staff members that we welcome in this issue. Jenny Donnelly the Admin Officer & the Haemophilia Resident (name TBA).

Queensland Haemophilia Centres Contact Details

ADULTS CLINIC (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
Michael Hockey — Physiotherapist	3646-8135
Maureen Spilsbury — Advanced Social Worker (Mon-Thur)	3646-8769
Desdemona (Mona) Chong – Advanced Psychologist (Fridays)	3646-8769

CHILDRENS CLINIC (LCCH)

Dr Simon Brown — Haematologist	3068-1111
Haemophilia Resident	TBA
Joanna McCosker – Clinical Nurse Consultant	043 8792 063
After hours—call switch and ask to speak with on-call haematology consultant or present to the emergency department	3068 1111
Wendy Poulsen — Physiotherapist	3068-1111
Moana Harlen — Senior Psychologist	3068-4180

HAEMOPHILIA CLINICS

RBWH

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

LCCH

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 (no direct number yet)

OUTREACH CLINICS

Gold Coast Hospital, Toowoomba General Hospital, Nambour Hospital, Cairns Base & Townsville Hospitals:

Book through Joanna at LCCH and Beryl at RBWH

New Year, New Resolutions

If you don't know where you're going, any road will get you there. **– Lewis Carroll (**Alice in Wonderland)

Good bye 2014, hello 2015. A new year often brings on fresh optimism about setting new resolutions. However, common resolutions like "be a better person", "be healthier" and "achieve more" are vague concepts that cannot tell you if you are on the right track. The concept of SMART goals has been developed to help with this. SMART stands for

S – Specific

M – Measurable

A – Attainable

R – Relevant

T – Time-bound

For example, if you have been told by your GP to "exercise more to reduce blood pressure" and this is important for you, you have to develop a SMART goal around "exercise more". It could look like this:

S – Specific: walk one round in the park

M – Measurable: 20 minutes

A – Attainable: three times a week, Monday, Wednesday, Friday

R – Relevant: To lower blood pressure

T – Time-bound: Review in a week

By being very specific, you can

then see how well you are sticking to your goal and make changes accordingly to success.

However, before you start working on achieving your SMART goals, it is also important to realise that changing one habit at a time sets you up for greater success. In his book, The Power of Less, Leo Babauta outlines his method of success for creating new habits. He says, "*the only way you'll form long-lasting habits is by applying the Power of Less: focus on one habit at a time, one month at a time, so that you'll be able to focus all your energy on creating that one habit.*" He argues that there is 100% failure for forming multiple habits at once, and a 50-80% success if you do just one habit at a time.

Hence, while you may have many SMART goals, just choose one to focus on for a month, before moving on the next. So this Summer, let's get organised by deciding which direction you want to head towards, and which single road you want to focus on!

You can find out more information about creating new habits in this book: The Power of Less: The Fine Art of Limiting Yourself to the Essential...in Business and in Life by Leo Babauta

Mona Chong - Dr Desdemona Chong
Clinical Psychologist
Qld Haemophilia Centre (Fri)

Maureen Spilsbury
Advanced Social Worker
Qld Haemophilia Centre (Mon- Thurs)

A Word On Parking (at Lady Cilento)

Many people have found it difficult to find affordable parking near the new Lady Cilento Children's Hospital at South Brisbane. The LC is located within the Brisbane 2 hour parking restriction area which means you can't park for more than two hours unless the signs tell you otherwise. It's not just patients, all the staff also need car parking too, so it is very crowed on the side streets at present.

We are asking parents to share their stories of the best parking options and will publish our findings in the next issue. Some people are using the designated parking buildings, others are parking outside the 2 hour restriction area and then taking a bus to the hospital. If the cost of parking is stopping you from getting your child to appointments always let the clinical staff know as they cannot look for solutions if they don't know you have a problem and there may be other options we can explore for you.

Merry Christmas and a Happy New Year!

Christmas and New Year celebrations are here AGAIN?

The start of a New Year is a perfect excuse to build new goals and activities into your life and is a good opportunity to make new friends. C.S. Lewis said *"Friendship is born at that moment when one person says to another: "What!" You Too? I thought I was the only one."*
I have listed a few simple suggestions about how to find that "elusive" new venture in the coming year.

Did you know that….?
You can visit your local library or go online to look at the range of activities they plan for all ages. You will find a range of free activities plus it's a chance to socialise with others in an informal setting. For example…

The libraries of the Gold Coast offer a lot of activities and information sessions including computing classes for both beginners and those who want to learn more. Book clubs and events for book lovers are a great place to meet others. The libraries offer a range of activities including craft groups, job seeking information, film clubs and information sessions to help deal with life e.g.. practical steps to take if someone you know is depressed and understanding eating disorders.

Many local councils also offer Social Support Programs for seniors, adults and children as well as for families. For example seniors living in the metropolitan area can have a look at *http://www.brisbane.qld.gov.au* for information about local events for seniors and over 50's. Current activities include bowling, yoga, book clubs, dancing or tai chi, Mahjong, computer classes, gardening, local and family history, craft workshops and more.

Toowoomba, Queensland's beautiful "Garden City" has a host of activities in their gorgeous parks providing a wonderful opportunity to get out and about in the fresh air. The Jondaryan Woolshed has a host of School Holiday activities which offer a glimpse into country life including sheep shearing and feeding the farmyard animals for your kids or Grandkids.

The Cairns Regional Council provides a program called "Active Living Free Fitness" at the picturesque Cairns Esplanade. The classes are introductory level and include Active Living Seniors Steady Steps, Active Living Tai Chi and Active Living Aqua Aerobics.

For those living outside of these areas head to your local Council and Library website and have a look for activities in your local area. Give me a call if you need a hand finding a new and exciting activity for the New Year.

HCV Update
I have printed copies of the information **"Need-to-Know News on Hepatitis C Treatment – 24/07/2014"** from Hepatitis Australia. The information includes an outline of two new treatments currently being assessed for use in Australia. Have a look at the information on their website or give me a call if you want a hard copy.

Psychosocial Workshops
Can I encourage you to make contact if you are interested in attending or have suggestions to share about any of the 2015 psychosocial workshops Mona has outlined in this newsletter(p6)? We want to make the most of this valuable opportunity and would value your input.

Book and Biscuit Group - I am still keen to start a group which will meet to work through the book called **Explain Pain** by David Butler and Lorimer Mosely. Watch out for more information in the next Newsletter but let me know if you have suggestions about the HOW, WHERE, WHAT and WHO of planning the get-togethers.

Quality of Life Alert! – Mona and I are hoping to be able to distribute our Quality of Life research questionnaires in early 2015. Keep an eye out for mail relating to the survey and updates about progress in future newsletters. We are currently in the process of gaining Ethics Approval for the project.
I hope that you all have a wonderful Christmas whatever you are doing. I will finish with a great quote from Charles Dickens – *"I will honor Christmas in my heart, and try to keep it all the year".*

Maureen Spilsbury
Advanced Social Worker – Haemophilia
(Monday to Thursday)
Ph 07 3646 8769
Page me through switch ph 07 3646 8111 on pager 57690
(Mona is in the office on Fridays)

Adult Patient GP Survey Needs Your Help!

Do YOU have a GP?

Are you over 18?

Does your GP understand your haemophilia?

Do you see your GP a lot or a little?

Is your GP easy to talk to?

Whatever the answers, **WE NEED YOUR HELP!**

We want to find out from YOU what you think about visiting the GP.

The nurses at the Haemophilia Centre at the RBWH are doing some research into the role of the General Practitioner in healthy living, men's health checks and ageing for men with haemophilia.

Please complete the short on-line survey at: *https://www.surveymonkey.com/s/8MQS5KY* or call Olivia or Beryl on 3646-5727 for a paper copy.

The aim of this research is to discover how we can help you to have **proactive**, **productive** visits to the GP. We would like to help bridge the gap between the Haemophilia Treatment Centre and the GP.

AND THE BEST BIT?

Everyone who completes the survey can go into a prize draw to win a $100 **Bunnings voucher**, so you can get going with some DIY projects this summer!

Exciting Funding Award Makes Forums Possible

The Queensland Haemophilia Centre has been announced as the recipient of the 2014 'Changing Possibilities in Haemophilia® grant program. *(http://www.changingpossibilities.com.au/grant-recipients-2014).*

This means the Centre has secured funding to run **four full-day workshops** covering a range of psychosocial topics that may be relevant for the haemophilia community. The topics will focus on increasing one's resilience and quality of life, and are non-medical in nature. Themes identified so far include;
1) Pain Management,
2)Communication,
3) Relationship Issues for Women who Carry the Haemophilia Gene;
& 4) Relaxation for dealing with Stress and Anxiety.

The first workshop will be targeted at women who carry the gene, and their significant other / family members. This workshop will provide a platform for knowledge sharing, skills-building and peer support. We hope to hold the first workshop in February/ March 2015.

While the workshops will be held in metropolitan Brisbane, it is possible for the Centre to fund eligible regional individuals to travel down to attend the workshops.

In order to maximise the funding, this is what we need you to do:

Contact Maureen or Mona on 07 3646 8769:-

- If you have questions about the workshops
- To express your interest in attending the first workshop if you are keen
- Have any suggestions on other topics you would like to see covered

We look forward to hearing from you!

Watch this space!!

Mona Chong - Dr Desdemona Chong
Clinical Psychologist
and
Maureen Spilsbury
Advanced Social Worker
Ph 3646 8769

Inhibitors—some basic answers

Many families and individuals with haemophilia have mentioned Inhibitors recently. This has come up from many sources. With new families and new children on treatment comes new inhibitor diagnoses. From Dr Google comes research and news of risk of inhibitors from using different products. So what is the truth on inhibitors? Here's a look at what we know…

What are inhibitors?

Inhibitors develop when the body's immune system stops accepting the factor as a normal part of blood. The body thinks the factor is a foreign substance and tries to destroy it using antibodies called inhibitors (because they inhibit the clotting factor from working) before it can stop the bleeding. This is similar to what happens when a person receives a transplanted organ. The body's immune system sees the organ as foreign & tries to reject it.

Historically, the majority of inhibitors have been reported to develop during childhood. In persons with severe haemophilia A, on average inhibitor development occurres between 1 and 2 years of age and after 9-12 treatments. Inhibitor risk is greatest during the first 50 exposures to recombinant (genetically engineered) factor VIII. Although the risk greatly diminishes after 200 treatment days, 1 in 50 people with mild or moderate haemophilia A can develop new inhibitors during adulthood.

Persons with haemophilia with inhibitors are at similar risk of incapacity from bleeding into their joints as those without inhibitors – but will not usually respond to factor replacement and require specific treatment from the Haemophilia Treatment Centre

Are inhibitors common?

Approximately 15-25% of people with severe haemophilia A will develop an inhibitor. Persons with haemophilia B are much less likely to develop inhibitors. Most people develop these inhibitors when they are very young children, soon after they receive their first infusions of factor VIII concentrate. Some people develop them later in life.

It would appear that the risk of inhibitor development in severe haemophilia A is complex and multi -factorial. Fortunately, in 1 out of 2 of cases the inhibitors disappear on their own, or with treatment, within, on average, 9 months. For the others, the inhibitors persist and are a serious problem.

In haemophilia B, inhibitors are much rarer. They affect about 1 in 100 people. In most cases these inhibitors develop after the first infusions of factor IX concentrate. Unfortunately, inhibitors in people with haemophilia B can be extremely serious because they can be accompanied by allergic reactions if factor IX is infused.

Why do inhibitors develop?

Doctors do not know exactly why inhibitors develop in some persons with haemophilia and not in others. They think there are two possible causes.

The first possible cause is environmental. Doctors think that something in the factor concentrate triggers the body's immune system to react. For this reason, if a product is working well, and has not caused inhibitors to develop, doctors usually won't recommend a switch to a different product.

Recently there has been talk of some products causing inhibitors in untreated patients and a precautionary Medical Advisory has been issued by the National Hemophilia Foundation (NHF) in the USA who found elevated inhibitor rates for one specific product (Kogenate FS / Helixate NexGen) in previously untreated patients with haemophilia A. Under the new Australian tender process for the supply of recombinant Factor products Kogenate FS* (Bayer) is being phased out after a transition period so this shouldn't be a problem here.

The second possible cause is genetic. Some haemophiliacs with a certain type of mutation of their factor VIII gene may be more prone to developing inhibitors. This explains why development of inhibitors sometimes runs in a family because they share the same gene mutation. This genetic cause of inhibitor development is also very possible in haemophilia B.

Diagnosis

A blood test is used to diagnose inhibitors. The blood test measures inhibitor levels (called inhibitor titres) in the blood. The amount of inhibitor titres is measured in Bethesda units (BU). The higher the number (of Bethesda units), the more inhibitor is present.

Inhibitors are also labelled "low responding" or "high responding" based on how strongly a person's immune system reacts or responds to repeated exposure to factor concentrate. When people with high-responding inhibitors receive factor concentrates, the inhibitor levels increase quickly. The increased inhibitor titre prevents the factor clotting concentrates from stopping or preventing a bleeding episode.
When people with low-responding inhibitors receive factor concentrates, the inhibitor levels do not rise. Therefore, people with low-responding inhibitors can usually still use factor clotting concentrates to stop or prevent a bleeding episode.

Treatment

Treating people who have inhibitors is complex. Some treatments for people with inhibitors include the following:

Immune Tolerance Induction (ITI) Therapy which is to get the body, and its immune system, used to the infusion of factor VIII so that it no longer rejects it. With ITI therapy, people receive large amounts of clotting factor concentrates every day for many weeks or months. These therapies

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Tiny Puzzle Pieces

When you receive diagnoses, go in for a multitude of tests, and have to take handfuls of pills, it becomes impossible to see yourself as whole. Everything gets broken down into what isn't functioning today—what isn't working. You have to figure out which doctor to call because no one doctor treats everything.

You have a doctor for haemophilia and a different one for gynaecology. When you go to ENT, the ear doctor doesn't deal with the sinuses and most definitely doesn't deal with the throat, so you see several doctors and at the end of the day, you start to see yourself as broken pieces.

I found out at midnight one day last fall that another piece of me had broken. This time, it was my pancreas. I'm not sure if I'm supposed to be sad about this. How can you grieve for an organ you've never really thought about before?

It's difficult to live life with even one diagnosis, as many of you know. Chronic illness can be very limiting, even though you try not to let it limit you. But if you do not know anything different, you adjust. You learn to accept what you can't do, even if there is, at times, a twinge of pain for the way of life you never get to have.

It frightens me when I read on different online discussion boards that young people who have similar or the same diagnoses as mine have passed away. I know in life that we're never guaranteed a certain amount of time, but it gets me thinking about what I could do differently that they didn't do. How can I know my body better or stop ignoring problems that I was just hoping would go away?

Medical alert bracelets are a necessity when you have health issues that could require very specific emergency care. Throughout college, I had these really adorable interchangeable beaded bands. The metal portion was engraved on both sides. Then I reached a point where I needed to carry a piece of paper with basic information—my doctors, my allergies, my medications, and my health conditions. Then that list grew. I have a lot of allergies and have at times in my life been on more medications than the number of years I've been alive.
This page is always with me. I have copies in my purse and in the car. I started to think about who is important, and who might need these forms just in case I was around a friend and something happened.

The first person to get a copy of this form was my best friend, Shelly, for obvious reasons. She's around a lot, has taken me to the ER before, and she travels with me. Providing her with this information was an afterthought, as she mostly knew everything.

But giving someone a copy of my health from is a very different kind of moment to when I pull out my pills around mealtime at conferences and my friends joke around, saying, "Oh, it's Sami's pill time. Anything good?" My pancreas enzyme pills, which help me break down and absorb the food I eat, are made from pig pancreas, and that can be kind of fun to joke about. Yet when someone looks at your entire medical history laid out on a single -spaced page, it's the most bare and exposed you can feel.

I know that at some point I'll be comfortable in my own medical information skin. I am always open to answering any questions people have, but I'm always a little startled when people throw things out there like, "Can you have kids with your clotting disorder?" or, "How many pills do you take a day?"

I answer because I know that someone has to. There have to be people out there who are willing to take a step forward to make having a chronic disease less of a hidden or publicly discomfiting situation. It's my body that's a bit broken, not my personality, and not my spirit. I'll speak up loud if I have to because, well, my voice is naturally loud and I don't know how to be any other way.

It doesn't really matter if it's a 15-piece puzzle set, or one with a thousand pieces, because at the end of the day it still creates the same picture: I'm me. The pieces collected in my past have never defined me, and there isn't a reason for them to do so now. Each piece just allows me to see more clearly and gain a greater sense of self.

Edited for size from an article by Sami Jankins first published in Hemaware 2013. Full article can be viewed at: http://www.hemaware.org/blogs/chronicles-cheerful-clotter/tiny-puzzle-pieces

Aged-Care Options; how to choose what's best.

As you, your parents and relatives age or become more vulnerable, you may be faced with the task of helping decide on a move into an aged care facility.

Moving from living independently to receiving aged-care services can be an emotional time for all concerned, so it's important to understand the available options ahead of making a decision.

PLAN EARLY

Considering aged-care options well in advance will give you time to understand the system and what type of timeframes are involved.

Before you determine if a government funded aged-care home could be the right place, or whether a home-care package is better, an Aged-Care Assessment Team (ACAT) will have to assess situation.

GP's can make a referral to a local ACAT (free appointment) for you. They will visit you or your parents to assess their needs. Once an application has been approved it's valid for 12 months.

SERVICES PROVIDE AT AGED-CARE FACILITIES.

Accredited aged-care facilities provide accommodation, meals, recreation, social activities and nursing care. The majority offer both low-level care (help with everyday needs, like meals) and high-level care (offering a lot of assistance). Always do your research and find the right home – one that can meet the care needs Into the future. A good time to talk about what is available in your area is during the ACAT assessment.

WHAT FEES AND CHARGES DO YOU PAY IN AGED-CARE?

The Government recently introduced changes to aged-care legislation as part of its ***Living Longer Living Better*** reforms. A key reform is a new means-test in residential aged care that decides how much needs to be contributed towards care and accommodation, based on both assets (property & possessions) and income.

- Everyone entering an aged-care facility is required to pay a basic daily fee of $46.50 per day (85% of the single basic Aged Pension rate), which covers costs such as power, laundry, and meals.
- You can also choose to pay additional fees for extra (optional) services, such as a bigger room or more extensive leisure choices.
- Some people may be required to pay a means-tested care fee. This is based on an estimate of your income and assets. These fees are capped at $25,000 a year, with a limit of $60,000 over a lifetime (the caps are indexed).
- Depending on income & assets you may also have to pay for all or some of the accommodation. Payment choices include a lump sum called a Refundable Accommodation Deposit (RAD), a periodic charge called a Daily Accommodation Payment (DAP), or a combination of both.

CAN I RECEIVE CARE IN MY OWN HOME INSTEAD?

Living in your own home can be a successful option (with help) as you get older. Home-care packages offer varying levels of assistance. Everyone pays a basic fee of up to 17.5% of the single basic Aged Pension towards a home-care package.

If you have a yearly income above $24,835.20 for a single person or separated couple (or $38,552.80 for a couple living together), you may also be asked to contribute an income-tested care fee. This assessment excludes the value of your home or other assets.

The Government is increasing the number of home-care packages over the next ten years and there are annual and lifetime caps on these fees. . Home based income-tested care fees will be capped at $5,000 per year for single pensioners and $10,000 a year for pensioner couples, with a lifetime cap of $60,000. Once there caps are reached, you will not be asked to pay any more income-tested care fees.

The Government provides guidance on the options available – for more information, call **My Aged Care** on 1800 200 422 or visit the Aged Care website (*www.myagedcare.gov.au*).

Edited for size from an article by Charlotte Francis where she discusses with Val Nigel, (author of 'Aged care, the complete Australian guide') options for choosing the best care for aging parents or yourself.

A Magic Trick You Can Try At Home

This is called the Magic Envelope Trick.

The magician asks a volunteer to write down four numbers on a piece of paper. The magician asks a volunteer to TOTAL up the numbers.
The magician opens a sealed envelop and it has the same number as the TOTAL!

Supplies
You will need two pieces of paper; a pen; and an envelope

The Secret
Before the show, write down a four figure number that is 2 times the current year's date. For example, in the year 2000, the number would = 4000. In the year 2015 the number would = 4030

Seal the paper in the envelope

At the show ask a volunteer to write down the year they were born.

Ask them to write down the year of an important event in their life (for example the year they started school or the year they lost their first tooth).

Ask them to write down their age (how many years old will you be at the end of the current year?)

Ask them to write down the number of years that have passed since the important event.

These numbers HAVE to be right 'cause it's all about maths! (if it's been 4 years since the event and they write down 3 it wont work)

The years have to be whole numbers (they can't say 6 and a half years old ...it has to be seven

Have the assistant TOTAL the 4 numbers.

Open the envelope. The TOTAL will be the same as the number you already wrote down!

For Example
The year is 2015 (Times two is 2030 which is the number you have written on the paper in the envelope.

Kaitlyn was born in 2000

She will be 15 this year

Kaitlyn started school in 2005

In 2015 she will celebrate her 10th anniversary since she started school.

2000 + 15 + 2005 + 10 = 4030 the same number as the number in the envelope.

Tech Corner for Kids

Stay sharp with these three brain -boosting apps...

Lumosity

For: iOS and Android *(free).*

Lumosity is one of the best known apps for braion training and is designed to test memory and attention. You choose which skills you want to improve – attention, speed, flexibility or problem solving -= and the app suggest games for you to play. A paid subscription will give you access to more games.

Clockwork Brain

For: iOS *(free).*

This is a game based app created to test cognitive abilities such as visual/ spatial, logic, language, arithmetic and memory. Sprocket, a clockwork robot, and his best friend Miranda, train you by providing help, advice and feedback on your performance.

Mind Games

For: iOS, Android and Windows *(free).*

There are 13 games in this app, which focuses on improving your cognitive skills. Practice your ability to anticipate improve your attention span or learn tricks to memorise a series of names or numbers. The app charts your progress and includes a global top scores list.

Self-Infusions help you manage bleeds

Growing up with a bleeding disorder means you've got to know how to take care of yourself when it matters most. Maybe you learned to self-infuse at youth camp, and that's a great first step. Self-infusion helps you manage your bleeding disorder from the comfort of home. It's a major part of getting older and helping out more with your health. You can be a big help to your mum and dad if you learn the basics of self-infusing. Be sure an adult supervises you to make sure you're doing everything safely and correctly!

Here are six steps for self-infusing at home:

1. Get ready.
Do a good job cleaning up the area you'll use to infuse. Be sure you have plenty of light nearby to keep a sharp eye on what you're doing. First, wash your hands and arms with soap up to your elbows before you get started—just like a doctor! Don't forget to wear your latex gloves!

2. Prepare your area.
Now it's time to get organised. Gather all of your supplies and put them in the area you've cleaned up for your infusion. Check the label on your factor to make sure you've got the right medicine, and then mix the factor.

3. Get factor ready.
Before you can get the factor into your body, where it's needed most, you'll first need to get it into the syringe. Get an adult to help you prepare the needle and syringe. Ask for help getting the mixed factor into the syringe.

4. Find a good vein.
Look for a good spot to inject your factor. It might be on the back of your hand, on the inside or back of your lower arm, or on the inside of your arm at the bend of your elbow. Put on a tourniquet (a band tied tightly around the arm) to help the veins to "stand at attention" so that you can see, feel and use them for infusion of factor. Then, using an alcohol swab, clean the part of your hand or arm that will be infused.

5. You're ready to infuse!
With the help of an adult, remove the cover of your needle and insert it. You'll probably see some blood, and that's OK! "Pop" the tourniquet after the needle is inserted into the vein, when you see blood in the tubing, and before you start pushing in the factor. Next, slowly push the syringe plunger down as you inject factor into your vein. When the syringe is empty, remove the needle. Then, hold a gauze pad on the area you injected for at least one minute. You can cover it with your favorite Band-Aid®!

6. Write it down.
Fill out myABDR to keep a record of your infusion. Guess what? You're all done! Good job. -Infusing wasn't so hard, now, was it?

Edited for size from an article by January W. Payne first published in Hemaware 2012.
http://www.hemaware.org/story/kids-guide-self-infusions
Illustrations by John Haslam

Treating Bleeds

Do you know the three things you must do if you have a bleed?

1. You need to use (P.) R.I.C.E. (apply **PRESSURE**); **REST** up; put a cold **ICE** pack over the spot; and **ELEVATION** if this is possible.
2. Tell your parent or guardian / carer (and write it up in myABDR)
3. Infuse with factor (treatment) as directed by your doctor.

Hep C – Help Us With The Govt. Inquiry

From HFA E-News...

Are you an Australian with hep C and a bleeding disorder? Or a partner/family member?

Please help us to tell the Australian Government what impact hepatitis C has on you and your life – and what strategies would help to improve your situation.

The Australian Government House of Representatives Standing Committee on Health is conducting an inquiry into hepatitis C in Australia. HFA will make a submission on the issues for the bleeding disorders community.

HOW CAN YOU HELP?

We need your help with real life examples for the HFA submission.

Please take 5 mins to complete the HFA hep C member survey and tell your story –

GO TO *https://www.surveymonkey.com/r/?sm=71sdQw39mzfcsAWx5SHFig%3d%3d*

TO START THE SURVEY

Please complete the survey by Wednesday 14 January 2015.

WHAT IS THE INQUIRY INVESTIGATING?

The Inquiry is looking at particular issues, including:

- How common hepatitis C is in Australia
- The costs associated with treating the short term and long term impacts of hepatitis C
- Methods to improve prevention of new hepatitis C infections
- And methods to reduce the stigma with a positive diagnosis through:
    - The public health system
    - Public health awareness and prevention campaigns
    - Non-government organisation health awareness and prevention programs.

You may also wish to make your own submission.

The deadline for submissions is Friday 27 February 2015.

For more information, go to www.aph.gov.au/hepatitisC.

Inhibitors...

Continued from p7

last anywhere up to 36 months. They are successful with 2 out of 3 people with severe haemophilia A and inhibitors.

Special blood products can be used to treat bleeding in people with high titre inhibitors. They are called bypassing agents. Instead of replacing the missing factor, they go around (or bypass) the factors that are blocked by the inhibitor to help the body form a normal clot.

Doctors have over 25 years of experience in helping people with haemophilia A get rid of their inhibitors but they have much less experience with immune tolerance therapy in haemophilia B. This is because the number of people with haemophilia B and inhibitors is very small and unfortunately, ITT seems to work less well with these people. What's more, many haemophilia B patients with inhibitors have severe allergic reactions to the continued infusion of factor IX concentrates. This can make ITT a risky therapy.

Research & the Future

Despite the very serious nature of this haemophilia complication, there are reasons for a person with an inhibitor to be optimistic. Never has there been more interest in the problem of inhibitor development. Additional research will increase our understanding of inhibitors and knowing more about why some people develop inhibitors and others do not will help doctors predict who will develop an inhibitor before treatment is started. This should lead to a decreased rate of inhibitors in the future and enable doctors to treat this problem more effectively and perhaps prevent it altogether.

Edited for size from several articles. For original articles information see:

http://www.cdc.gov/ncbddd/hemophilia/inhibitors.html

http://www.hemophilia.org/Newsroom/Medical-Advisories/Medical-Advisory-417-Assessment-of-Possible-Increased-Risk-of-Inhibitors-in-Specific-Recombinant-FVIII-Replacement-Concentrates-in-Previously-Untreated-Patients-PUPS

http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-complications-of-hemophilia/inhibitors/

Inhibiters in Hemophilia: A Primer. Fourth Edition By Donna M. DiMichele *http://www1.wfh.org/publication/files/pdf-1122.pdf*

Long Acting Factor IX for Surgery Bleeding

A study in the *British Journal of Haemotology* shows that long-acting recombinant factor IX Fc fusion protein (rFIXFc) can effectively control perioperative bleeding in major and minor surgeries, with blood loss being similar among subjects with and without haemophilia.

A global team of researchers examined rFIXFc in 123 men with moderately-severe to severe haemophilia B. The patients were already using factor IX (FIX) products. Patients received rFIXFc weekly prophylaxis, individualized interval prophylaxis, episodic treatment / on-demand, or perioperative management instead of other FIX products. If patients required major surgery – minor surgery was qualified as not incorporating the use of anaesthesia – they were automatically enrolled in the perioperative management arm.

Amongst the participants there were 14 major surgeries. The most common frequent type of surgery was orthopaedic, which was expected by the researchers in haemophilia patients. Four patients had 1 target joint and 4 subjects had >1 target joint. There were 15 minor surgeries performed on the patients, which were mostly dental procedures.

Almost all of the patients (11 of 12 total) received an initial rFIXFc prophylaxis regimen before surgery; the last patient received episodic treatment before surgery. Weekly doses were the most common. Most of the surgeries (12 procedures) only required 1 administration of rFIXFc to maintain haemostasis during the surgical period, defined as the time from the presurgery dose to end of surgery. Most subjects received 1 -3 infusions on the day of surgery, and a total of 2-3 infusions during postoperative days 1-3. In most surgeries (9 procedures), the recommended doses were used; however, in the other 4 surgeries, the actual doses differed from the recommended dosing rate (higher or lower, more or less frequent dosing).

In all surgeries, haemostasis levels were rated good (1/14 surgeries) or excellent (13/14 surgeries). Haemostasis was rated excellent for 10 out of 12 minor surgeries, good in 1 surgery, and fair in 1 additional surgery. Evaluations were not available in 3 minor surgeries.

Less than 1 adverse event was reported in 10 out of 12 major surgery patients. One patient reported anaemia and dizziness. Three major surgery patients reported experienced less than 1 serious adverse event during the surgical and rehabilitation period. The 6 adverse events reported were assessed, and found to be unrelated to rFIXFc treatment. No patients experienced anaphylactic or vascular thrombotic events during the study period.

Edited for size from an article by Rachel Lutz. Full article available from: http://www.hcplive.com/publications/hemophilia-reports/2014/october2014/rFIXFc-Controls-Hemophilic-Patient-Perioperative-Bleeding

New Generation Recombinant FVIII

Australia recently approved a new recombinant FVIII product (called Nuwiq®) for treatment and prophylaxis of bleeding in patients of all ages with haemophilia A. This recombinant FVIII has a high affinity for the von Willebrand coagulation factor.

This recombinant FVIII closely resembles naturally occurring FVIII. It was studied for efficacy in surgical procedures & for prevention and treatment of bleedings. In two studies the bleeding rates for spontaneous bleeds during prophylaxis was 'zero'. In 'on-demand' treatment the efficacy for the treatment of bleeds was excellent or good in 94.4% of bleeds.

The immunogenicity of Nuwiq® was evaluated in 135 previously treated patients and no one developed inhibitors.

Edited for size from a press release by; Octapharma Canada 10 Nov 2014

Zero bleeds or on-demand therapy?

Is zero bleeds through prophylaxis better than on-demand therapy?

A recent study by A Gringeri et al, published in Haemophilia (2014:20,459-463) looked at the impact of any joint bleed and the desirability of aiming for zero bleeding episodes to avoid joint damage.

They reviewed several studies of bleeding within the joints and they looked at both clinical and subclinical bleeds and their impacts on arthropathy and quality of life.

They found that patients with severe haemophilia treated on-demand experienced an average of 9-18 times a year but this could be much higher; and they acknowledge that prophylaxis substantially reduces the incidence of bleeding but they ask is reduction enough, or should we aim for zero bleeds?

They cited several studies that showed bleeding within joints can lead to progressive joint destruction. This was true for synovial membrane and cartilage. Collectively the studies they looked at showed that you need less than 3 bleeds a year if you are going to maintain healthy joints.

They also reviewed subclinical joint bleeding and concluded that they do exist because of joint abnormalities in patients who reported as having no joint bleeds. They concluded that damaged joints severe enough to need orthopaedic correction can be caused by subclinical bleeds without evident pain or swelling.

The evidence was even greater when looking at clinical joint bleeding. Comparatively less joint damage and less limitations in daily activities was observed in high dose prophylaxis and low (less than 4 per annum) bleeds.

Finally the study looked at quality of life measures and they could show that greater than 3 bleeds a year resulted in reduced QoL measures in both adults and children as well as increased school absenteeism in children.

The study was unable to determine how many bleeds caused joint damage but they were sufficiently impressed by the evidence to argue for the need to aim for zero bleeds, especially in joints, not just a reduction in bleeding rates or detectable factor levels.

This is an interesting paper but it needs to be considered against cost of treatment and individual needs (severity, inhibitors etc) and lifestyle issues. If you are concerned about your own treatment and keeping bleeds down talk to the Haemophilia Treatment Centre staff about your own situation.

Haemophilia Awareness Week. It's a wrap...

Haemophilia Awareness Week and Red Cake Day was held this year from 12-18 October. HFQ and Haemophilia Foundation Australia (HFA) worked together to raise awareness about inherited bleeding disorders.

There was great interest in the week and we had many supporters to help us fundraise over the week. Red Cake Day proved to be a versatile concept for individuals and organisations along with schools and companies that wanted to do something highlighting the needs of people with bleeding disorders.

We had a fantastic response and sincerely thank each and every person who helped us fundraise and raise awareness during the week. It raised $1,127 in Queensland for programs and services within the state. Overall it raised about $15,000 in Australia, so we aim to build on this next year.

In Queensland we had four fundraising events and an additional 4 libraries and two hospitals had promotional displays using the promotional materials provided by HFA. Each event was different but we encourage all members to look at holding a local event next year to help us raise funds that support people affected by bleeding disorders in this state. A small commitment of baking mix and time can achieve wonderful results for those members who need our support the most.

Community Camp [20-22 Feb 2015]

The HFQ Community Camp provides a safety-focused, peer supervised, fun and recreational experience for people with bleeding disorders and their families. Sometimes it has felt like a young families camp, but the community camp provides an opportunity for anyone affected by haemophilia and other bleeding disorders to reconnect, have fun and exchange social support with other adult and child participants. Our scheduling includes time for rest and revitalisation and we adjust the camp program based on who is attending.

Although families usually spend the majority of their time participating in activities together, adult- and child-only time is also scheduled. The camp can accommodate the immediate family of the person with a bleeding disorder, including non affected siblings.

This years camp is booked for 20-22 February so please put the weekend aside and let Graham know if you want to attend. We are still waiting for word on funding for the camp but we always try to make this a low cost relaxing weekend for you to take a break and recharge amongst other people who know what it's like to live with a bleeding disorder.

HFQ has been committed to providing a retreat experience for people affected by haemophilia for a long time now and the need has not diminished. We are proud to have been able to and continue to provide summers of joy, confidence, support, and hope for these people and their families.

The Community Camp is appreciated and cared about by campers and their families alike, but part of what makes each camper's experience so wonderful is the program's ability to allow participants to gradually come to accept the differences that might exist for them due to their bleeding disorder. We have people tell us that camp has helped them to accept who they are and to engage in all the varied experiences they now enjoy with peers from school, their community, and whichever social groups they become a part of.

Campers sleep in family units grouped around a pool or individual cabins nearby (all units have fridges). Most of the time, families are together and supervision is the responsibility of the parents or caregivers. Medical support is not avalable on-site (Nambour Hospital is one hour away) so parents are expected to provide regular treatment-related care to their children as required.

We really need help to make this a great weekend for everyone so if youré able to volunteer your time it will make the community camp memorable as well as safe and secure. There are many different volunteer positions so if you are over 17 years of age and think you have what it takes to be a camp volunteer please call and talk to Graham.

Aged Care Terminology.

A GLOSSARY

High Care: Residential aged-care facility offering high-level care for people who require a lot of assistance with daily activities.

Low Care: Residential aged-care facility offering accommodation and help with some daily activities, such as meals and room cleaning.

Means-Testing: Assessment based on a person's income and assets to establish what they will contribute towards their residential aged-care facility fees.

Refundable Accommodation Deposit (RAD)**:** Aged-care payment option involving an up-front sum of money that acts as a refundable bond.

Daily Accommodation Payment (DAP)**:** An alternative method of payment involving a regular charge.

Source: www.agedcareguide.com.au

What do blood pressure numbers mean?

If you're an adult and have ever visited a doctor, you've probably had your blood pressure measured. General practitioners tend to obsess over blood pressure. But with good reason: hypertension, or persistently high blood pressure, can lead to heart disease, stroke and diabetes, the nation's biggest killers.

What is blood pressure?

Blood pressure refers to how hard the blood is pushing against the wall of arteries – these can be thought of as the pipes that deliver blood from the heart (the blood "pump") to the rest of the body.

This pressure is necessary for the blood to flow. Using a plumbing analogy, imagine the effect of a drop in water pressure to water flow from the garden hose. Blood pressure naturally varies throughout the day depending on posture, activity and stress. It can also be elevated or lowered as a consequence of illness or disease.

Stephen Hales, an 18th-century English clergyman and scientist, first measured the blood pressure of animals in a series of experiments that involved inserting tubes into their arteries. In one experiment with a horse, he describes the blood rising to eight feet in height in the tube!

Blood pressure measurement would almost certainly be unpopular if it involved inserting long glass tubes into people. Happily, Italian physician Scipione Riva-Rocci developed the blood pressure meter, in 1896.

Soon afterwards, Russian physician Nikolai Korotkoff discovered the sounds that can be heard with a stethoscope over the inner elbow while using a blood pressure meter. His technique remains the standard method for measuring blood pressure today.

Interestingly, the conventional blood pressure meter uses a column of liquid mercury to indicate the pressure. As mercury is so much denser than water or blood, even very elevated blood pressures result in it rising no more than about a foot.

This quirk of medical history gives us the modern

measurement unit for blood pressure: millimetres of mercury (mmHg). A blood pressure measurement of 140 mmHg literally means that the pressure will push up a column of liquid mercury 14 centimetres.

Two numbers are given when reporting blood pressures, such as 140/90 mmHg. The first number is the systolic blood pressure. This is the pressure when the heart is contracting to pump its content of blood into the circulation.

The second number is the diastolic blood pressure. This is the pressure when the heart is relaxing and is refilling with blood.

What is normal?

The National Heart Foundation guidelines define "normal" blood pressure withing the following range:

- Systolic blood pressure: 100 to 139 mmHg
- Diastolic blood pressure: 60 to 89 mmHg.

These thresholds are arbitrary, but a blood pressure less than 140/90 mmHg is not labelled as high.

We're also moving away from categorical descriptions of hypertension, based on blood pressure reading alone, towards a model where blood pressure is considered alongside other risk factors to determine whether drug or lifestyle interventions are needed.

Clinicians now calculate the patent's absolute cardiovascular disease risk: the probability they will have a heart attack or stroke in the short and medium term, which includes age and cholesterol levels. This algorithm can help them work out your absolute disease risk.

All adults should consider having their blood pressure measured at least once every two years. If it's elevated, and confirmed, you'll work with your GP to create a management plan to lower your blood pressure. This is likely to lifestyle changes such as:

- getting regular physical activity
- quitting smoking
- reducing the amount of salt you eat
- increasing the amount of potassium you consume (from foods such as parsley, dried apricots, some nuts, bamboo shoots, bananas, avocados, soybeans and bran)
- losing weight

Continued on page 18 →

Hepatitis C Treatment: An overview

For many years, hepatitis C has been treated with pegylated interferon and ribavirin, both of which cause significant side-effects. But with groundbreaking new treatments becoming available at least 9 out of 10 people could be cured of hepatitis C by taking a short course of tablets with very few side effects.

We've already seen improvements in treatment since the first direct acting antiviral medicines (DAAs) were subsidised by the government in April 2013, through the Pharmaceutical Benefits Scheme (PBS) for people with hepatitis C genotype 1. The improvements are going to keep on coming.

With more clinical trials in the pipeline, we expect new, affordable medicines to be subsidised through the PBS. Initially, these are likely to be shorter treatments, using a combination of pegylated interferon and DAAs to treat most people and drive the cure rate higher. Eventually, we'll see combinations of interferon-free oral medicines become available. These will have far fewer side-effects than current treatments and result in a high cure rate for most people. We also anticipate that these treatments will substantially improve the cure rate for people living with compensated cirrhosis, co-infections and other health problems.

Treatment for hepatitis C

Treatment is tailored according to the particular genotype or strain of hepatitis C that you have. The success of current treatments depend largely on your commitment to taking your prescribed medicines regularly, so be sure to follow your doctor's instructions consistently. On average, there is a 70% to 80% success rate with current treatments.

Your response to treatment is monitored by taking blood tests at intervals to measure the amount of virus in your blood. When the virus drops to undetectable levels during treatment and remains undetectable six months after treatment you're cured!

What's the next wave of hepatitis C treatment?

Two new hepatitis C treatments are currently being assessed for use in Australia, but we don't know when they'll be made available. They are;

Simeprevir (Olysio) For those with genotype 1 infection, it is a new direct-acting antiviral hepatitis C treatment (a second generation protease inhibitor), which would replace existing treatments with boceprevir and telaprevir (first generation protease inhibitors). Simeprevir would be combined with pegylated interferon and ribavirin.

The advantages of using simeprevir over existing treatment plans are that it is easier to take – one tablet daly with fewer complications, better tolerated (less side effects) and of shorter duration (of treatment - for most people). Simeprevir is not recommended for use if you have previously been treated with pegylated interferon and ribavirin and either boceprevir or telaprevir.

Sofosbuvir (Sovaldi) This is another new, direct-acting antiviral treatment (nucleotide polymerase inhibitor) that can be used to treat all genotypes of the hepatitis C virus. This once-a-day tablet is combined with other medicines. In addition to similar benefits to simeprevir, sofosbuvir also reduces (or eliminates) the need to use pegylated interferon which has significant side-effects for many people.

The new hepatitis C medicines are very expensive and will be subject to a rigorous process of expert assessment to establish safety and cost-effectiveness (see article on page XX), consequently, no one can tell with any certainty when you might have access to the next wave of hepatitis C medicines or other new medicines.

Don't put your health at risk by waiting too long

It's easy to understand why you might prefer to wait for interferon -free treatments to become available. However, by waiting, you could be putting your health at risk. If you're 40 years of age or over, you're likely to experience an accelerated rate of liver damage, which increases your risk of developing cirrhosis, liver cancer or liver failure. This is called the 'Liver Danger Zone'.

Liver disease may not be felt until the liver is significantly scarred but a liver check-up is nothing to worry about, it is simple, easy and it could save your life. Don't put your health at risk by waiting too long for treatment. Make an appointment with your doctor to have a liver health assessment at least once a year.

Edited for size from "Hepatitis C Treatment: An Overview."
Please see Maureen or Mona for a copy of the full article, or download at: http://static.squarespace.com/static/50ff0804e4b007d5a9abe0a5/t/53d09515e4b0a592985747eb/1406178581844/Hep+C+treatments.pdf

MyABDR update

WHAT'S NEW?

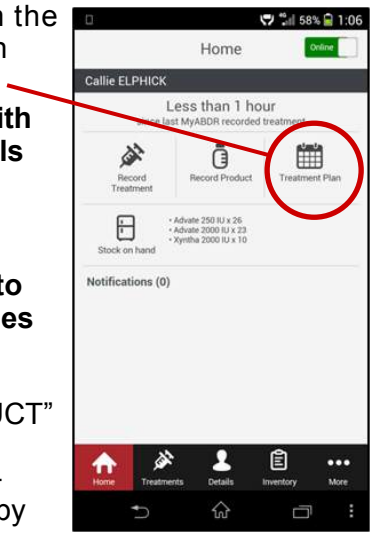
The latest release of MyABDR in November 2014 brought you more improvements and features:

- **Faster synchronisation**
- **Improved data saving**, so that your data is always captured in the central database, even if there is an error on your smartphone
- **A short-cut to your treatment plan** from the home page or screen
- **Bug fixes to deal with negative stock levels** some users have reported
- **Improved function to copy previous entries** for "ADD NEW TREATMENT" and "RECEIVED PRODUCT" to prevent the unintentional double-entries experienced by some users
- **Easier treatment product entry** – you will now only have the products in your treatment plan to choose from when you add products to your inventory.

UPDATING WITH THE NEW RELEASE

Update your smartphone with the latest release and make your life easier with the new fixes and features!

You will receive an email alerting you to the new release.



Your smartphone will alert you when an update becomes available.

For a cleaner installation, try uninstalling the existing MyABDR app on your smartphone and install the new version. *Make sure you go online and sync your data at the home page before you uninstall the app!*

If you use the web site, you don't need to do anything – you will just see the new features the next time you login.

NEED HELP?

Contact the MyABDR Support Team

Available 24hrs, 7 days a week
T: 13 000 BLOOD (13 000 25663)
E: myabdr@blood.gov.au

For more information on MyABDR, visit *www.haemophilia.org.au/myabdr*.

From the HFA and National Blood Authority MyABDR Team

Blood Pressure *cont...*

- drinking less alcohol.

Keep in mind that visiting the doctor can provoke anxiety, so the blood pressure can be elevated in response to the testing procedure itself. This has been called the "white coat effect".

If this is suspected, your GP might try recording your blood pressure over a number of visits, or use ambulatory or home blood pressure monitoring to get an accurate reading.

This article appeared in The Conversation on 29 September 2014, It was written by Michael Tam General Practitioner, and Conjoint Senior Lecturer at UNSW Australia and co-authored by Dr Patrick Khoury, a GP registrar at the General Practice Unit, Fairfield Hospital.

Are New Drugs Priced Out Of Reach?

What price a life?

It's twice as common as type 1 diabetes. It kills more Australians than HIV. One in every 100 of us lives with hepatitis C (HCV), but the disease receives little attention.

That's a lot of people but earlier this year, Australia's Pharmaceutical Benefits Advisory Committee (PBAC) declined to subsidise one of the new curative drugs for HCV called sofosbuvir.

The PBAC's reason for its refusal was the drug's potential impact on the health budget. The proposed Australian price has not been disclosed, but in the USA a three-month course of treatment costs US$84,000. The PBAC's decision reflects a concern felt around the world: ***at what price do we refuse treatments to people in need?***

A steep price

The current situation with hepatitis C recalls the fight over a decade ago for HIV drugs to be made affordable. The first drugs for HIV were approved in the US in the late 1980s, but the price of these patented medications prevented most people in heavily affected African countries from getting treatment until after 2001, when generic versions became available. This brought the price down from over US$10,000 per patient per year to just a few hundred dollars.

Almost six million people died of HIV in sub-Saharan Africa in the intervening years; a great many of these deaths would have been prevented with affordable drugs.

Now the first chapter of that story seems to be repeating itself. New treatments are in the pipeline for bleeding disorders and several life-saving medicines for HCV have also been developed, but they are priced out of our reach. International trade agreements, as they stand, will prevent universal access to affordable generic versions of the drugs.

Hepatitis C treatment makes an interesting case. HCV uptake in Australia is low. Out of the almost quarter of a million Australians living with the virus, but fewer than 2% are treated each year. Australia only recently approved "first-generation" drugs for HCV. These improved treatment efficacy and reduced treatment times. With "second generation" drugs such as sofosbuvir, which have shorter treatment duration, fewer side effects and higher efficacy, combination treatments should see increased uptake by much larger numbers of people.

But if the drug had been approved in Australia at the proposed price, the government would probably have to restrict access. If even 5% of the 230,000 Australians living with HCV were to receive combined treatment with sofosbuvir and ledipasvir (at US$94,000 per course), the drug cost alone would exceed US$1.1 billion. Yet researchers at the University of Liverpool have estimated that an entire three-month course of sofosbuvir can be produced for under US$140.

This is also true of some of the new long acting products under development to treat Haemophilia A & B. The claimed cost for the research and development of these products means the drug companies will ask a lot for them to be made available to us and our government is not in a position to pay more for blood products than it does already.

The first patents for the new HCV drugs are not due to expire for at least 15 years. Long after the cost of the drug's development has been recouped, but untill then, it appears patients and taxpayers will be expected to continue paying a huge price for this life-saving medicine.

This is likely to be the same experience as the new long acting haemophilia drugs finish their testing and come on to the world market. More than a decade after the first victories in the battle for affordable HIV drugs, the gulf between the priorities and profits of large pharmaceutical companies, the ability to pay by governments, and the needs of affected communities are again highlighted.

The new treatments for haemophilia should herald a revolution; a chronic and sometimes deadly disorder can now be brought under control and perhaps even cured. But unless affordable treatments are made universally available, people all over the world, in urgent need, will be left behind.

Nobody who recognises the human cost of medical conditions like HCV and bleeding disorders could question the value of these new medications. But even in wealthy countries such as Australia, we are being forced to question their price tags.

Based on an article "Hepatitis C drug out of reach for millions" 25 November 2014, in http://theconversation.com

Important Dates for HFQ Members

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

Fundraising BBQ (Bunnings) Bunnings Rothwell have given us two dates in February to hold a BBQ 12 & 15 February 2015. Please let Graham know if you can help

Community camp 2015 We've rebooked Noosa North Shore Retreat for 20 – 22 February 2015

Red Run Classic 17 May 2015

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

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

Please call Graham at the office on **07 3338 5645** for more info on any of these events and activities.

Red Run Classic

The Red Run Classic is a fun run organised by HFQ and Haemophilia Foundation Australia that takes place in Brisbane. We ran this event successfully in 2007, 2008, 2009, 2010 and 2013.

The Red Run Classic has cemented itself as a key running event in Brisbane competitive fun run calendar. In 2013, 649 runners competed in either the 5km or 10km run. Men, women, children and families all participated.

HFQ is again working in partnership with HFA and a prominent running event company to organise this much anticipated and highly successful event on 17 May 2015.

For the runners it's a great day to get a timed running result. For HFQ it's an opportunity to raise much needed money as we aim for self-sufficiency. If you work for, or know a business that might be willing to sponsor the event please let us know as it will help us keep costs down and raise even more money for people with bleeding disorders.

We also need volunteers on the day to make this a successful event so if you know a business sponsor, want to compete on the day of can offer your time as a volunteer, please let Graham know as we need everyone involved to make this a successful event.

To register your interest of for more information, please phone Graham on: 07 333 85645 or emal: info@hfq.org.au