

Iron Age News

September 2014

HAEMOCHROMATOSIS AWARENESS WEEK 2014

Once again, for one week during August, Haemochromatosis Australia and people all over Australia joined forces to focus attention on haemochromatosis. Newspaper and web articles, radio and TV advertisements and interviews, poster campaigns, information displays, art exhibitions and more drew attention to the most common genetic disorder in Australia. We know it worked because calls to the Haemochromatosis INFO LINE and visits to our website increased by 50% during August and early September. Thanks everyone who played their part.

Here are some images highlights of events and media coverage from the week.

Raising awareness of genetic disease



Inherited iron overload disorder

ARARAT

THIS week is Haemochromatosis Awareness Week, an inherited iron overload disorder affects many Australians including in Ararat. About one in 200 people suffer from the disease which sees the sufferer absorb too much iron from their diet which over time leads to iron overload. If undetected and untreated, the excess iron can cause organ or tissue damage and can potentially result in premature death. Early symptoms include feeling tired and flat with aching joints over a long time.

Carol gets word out on Haemochromatosis

By Tony Hastings

THIS week is Haemochromatosis Awareness Week and Narooma resident Carol Atkins is helping to get the word out.



Carol Atkins hands a pamphlet on Haemochromatosis to another woman, whose husband and sister are also affected.

Bloodletting for iron man Tony

REDHERRING returns and this time, it's a redhead who's discovered he was playing the muscle man - not just in the gym. And now, feeling very tired for years, he's said he would have to take a step back from the gym. "I was always tired and my joints were aching, especially my knees and hips," Mr. Moorhead discovered that he had a condition called haemochromatosis.



BLOOD DONOR: Tony Moorhead of Colimaal haemochromatosis, where the body stores too much iron.



Are you pumping too much iron?

Carol Atkins said, "I started making appointments with a Doctor, who started venesections immediately, drawing out lots of blood. I'm on 500ml a month. The excessive iron in the blood is taken away, and the body produces new blood, thus diluting the stored iron." "If people want to more information or to talk about it, they're more than welcome to come in to Odd Bods gym, or give me a call on 4476 5755, or contact me through the Facebook page: www.facebook.com/OddBodsHealthFitnessCentre"



Too much iron a big health issue



ANNUAL GENERAL MEETING HOBART - 8 AUGUST



Our AGM was held at the Menzies Research Institute, Hobart. The meeting followed a public information session and meeting of our volunteers and members. Forty people heard presentations

from haematologist Dr Nick Murphy, rheumatologist Dr Hilton Francis, Menzies researcher Barbara de Graaf, Menzies community coordinator Larissa Bartlett and Tasmania support group coordinator Jon Horlitt. Senator Catryna Bilyk officially opened Haemochromatosis Awareness Week for 2014 and spoke about the importance of raising awareness and early detection.



Thanks to Senator Bilyk, presenters, volunteers, members and visitors who made this a very successful event. A very big thank you to Menzies Research Institute for the free use of the facilities.

Appointment of Co-Patron

The members at the AGM were pleased to adopt a motion appointing a second patron for the society.

Professor Emeritus Lawrie Powell AC MD PhD FRACP FRCP (London)



Lawrie or 'Prof' as he is known to many in the haemochromatosis community is a world-renowned and highly respected researcher, academic and clinician in the field of liver disease and haemochromatosis. Lawrie has been a long term supporter and staunch ally of our group. We are pleased and honoured to welcome Lawrie as patron.



Lawrie joins Mrs Margaret Rankin AM as patron. Marg has been patron since 2010. Marg was the founder of our society and led the group as president for 21 years before handing over the reins to a new committee.

All sitting committee members nominated for reelection and were appointed unopposed. The committee are all volunteers. We meet once a month via teleconference and once a year at a full day committee conference following the AGM.

Introducing your 2014 - 15 committee members:



Ben Marris OAM BA (Social Work)

(President) Ben has been a committee member for several years and President for the past four years. Ben is the public face and tireless leader of the committee. Ben lives near Hobart, Tas.



Desma Wieringa RN RM BN

(Vice-President) Desma is a qualified nurse and midwife. She does a tremendous job handling the bulk of our INFO LINE calls. Desma lives in Adelaide, SA.



Tony Moorhead

(Secretary) Tony runs the business and administration of the association. He also publishes the newsletter, website and helps with communications. Tony lives on the Sunshine Coast in Qld.



James Stephenson FRAIA

(Treasurer) James is an architect who lives in Brisbane, Qld. James handles the tricky job of balancing our books and budgeting for the society.



Linda Rule is our membership coordinator and handles membership applications, renewals and updates. Linda lives on the Sunshine Coast, Qld.



Karin Calford B Soc Sci

Karin has taken on responsibility for fostering links with the primary health care sector and health professionals. Karin lives in Launceston, Tas.



Dr Katie Goot MBBS BSc FACRRM

Katie is a GP who lives and practices in Central Qld. Katie is our GP Liaison Officer and has developed training packages and resources for medical professionals.



Dr Dan Johnstone, PhD

Dan is a medical research scientist based in Sydney, NSW. He brings a scientific perspectives and important links to the committee.

GENETIC SCREENING

'To screen or not to screen?' This was the question asked of the expert panel at the conclusion of the Haemochromatosis Conference in May. The answer was resounding and unanimous 'Yes, we must have genetic screening for haemochromatosis'.

And so, following from the conference, I have worked with Professors Lawrie Powell, Martin Delatycki, John Olynyk and Katie Allen to develop a proposal for screening to put to the federal government. Our argument is that making genetic screening available to all Australians will not only save a great deal of unnecessary iron overload caused disease and save lives, it will also save money. It will save costs in the health system. It will have a benefit to the workforce through reduced sick leave. Further, it will result in a substantial increase in the number of young, healthy lifetime donors to the Blood Service.

On 2nd September we met at Senator Catryna Bilyk's office in Australian Parliament House. Unfortunately John was not able to attend but the rest of us then presented our case to Assistant Minister for Health Senator Fiona Nash. We also met with Shadow Minister for Health Catherine King.

We felt that our case was very well received. There is much more for our team to do before widespread screening becomes a reality, but we are optimistic that we have taken a significant step which should lead us towards our vision that **no Australian will suffer harm from haemochromatosis.**

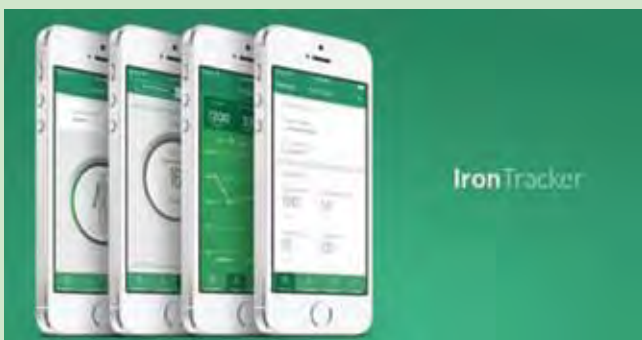
I look forward to keeping members informed.
Ben Marris, President



Genetic screening on the agenda.
Martin Delatycki, Lawrie Powell,
Asst Min Fiona Nash, Ben Marris, Katie Allen

IRON TRACKER APP FOR YOUR MOBILE DEVICES

Iron Tracker is a free App for your smartphone or tablet to help track your ferritin levels, venesection and test appointments and even which arm you last used.



Available in both Android from Google Play and iOS from Apple, this simple little App should be helpful to manage your treatment and might replace paper records or complicated spreadsheets for some.

The App was developed for the Canadian Hemochromatosis Society as a pro-bono project by faculty and staff from two Canadian Universities. It works just as well for Australian users. The team are keen to receive feedback and suggestions so please leave a review on relevant store site or send comments to feedback@ha.org.au.

HAEMOCHROMATOSIS HEALTH PATHWAY LAUNCHED

GPs, and other health professionals in the Hunter region of NSW now have easy access to up to date information to help them in diagnosing and treating haemochromatosis. Information about the genetic basis of the disease, screening of relatives, how to investigate an affected person, how to interpret the results of the investigations, how to decide if a person with haemochromatosis needs to see a specialist, and how to arrange venesection in the local area, has been summarised and published on the Hunter & New England HealthPathways website.

The website is used by GPs during consultations with patients and also includes patient information resources. Patient information is also directly available to patients on a companion website called Hunter & New England Patientinfo (<http://www.patientinfo.org.au>).

Haemochromatosis Australia have contributed to the development of this HealthPathway, and are working to ensure that it is adapted and published by other HealthPathways programs being established across many regions in Australia.

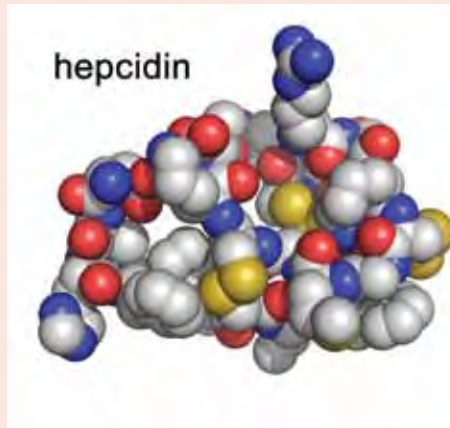
*Dr Margaret Lynch, Clinical Director
Hunter Medicare Local, Newcastle NSW*

RESEARCH WATCH - HEPCIDIN

While most of us can manage our iron overload through routine venesection, this is not feasible for everybody. Some people have a strong aversion to needles, others have blood vessels that are difficult to cannulate, and others may have non-iron-related anaemia that would be worsened by blood removal. For these reasons, there has been considerable interest in ways of controlling the small molecule **hepcidin**.

Hepcidin is a hormone that is produced by the liver and circulates in the bloodstream. Since its discovery in 2000, hepcidin has been a focal point of the iron research field, as it appears to be the master regulator of body iron levels, controlling how much iron is absorbed from the diet and how much is released from the

body's cells. People with haemochromatosis naturally have low hepcidin levels; this is believed to be what causes them to accumulate more iron than is healthy. Scientists believe that by



finding a way to increase hepcidin levels or activity, they will be able to restore normal iron control to haemochromatosis patients.

In a recent study, a research group in Boston screened over 10,000 different chemicals to see how they affected the production of hepcidin. From this screen they identified 16 chemicals that were capable of increasing hepcidin production. In particular, two of these chemicals, named ipriflavone and vorinostat, were particularly potent.

As this study only looked at the effects on cells grown in culture, a lot more work needs to be done to show that these chemicals are both safe and effective in animal models. But it provides a few good candidates for follow-up studies and may, in a few years time, lead to a suitable drug therapy for haemochromatosis patients who cannot tolerate regular venesection.

Dr Dan Johnstone PhD

VENESECTION CARE

We have probably all heard the basic tips for preparing for and recovering from venesections many times, but we all lead busy lives so it is easy to forget or overlook the simple things that can help a venesection go more smoothly.

- Drink plenty of fluids – starting the day before your appointment.
- In the three hours before your appointment, eat a good meal.
- If you have difficult veins, heat packs may help.
- Alternate your arms. Share the load!
- There are topical anaesthetic creams and patches that may help if you find the procedure painful. Ask your pharmacist or doctor.
- If possible, make the appointment for a time that suits you – when you're not rushed and stressed. Some people prefer mornings, others afternoons.
- Take a music player with your favourite music and headphones. There's nothing like a little distraction to take your mind off things.

- A brisk walk before the venesection may help dilate the veins. But don't overdo it and don't become dehydrated.



After the venesection:

- Take the time to rest for a short while. You may be busy but it's important to give yourself time to recover.
- Avoid heavy lifting and strenuous exercise for 24 hours.
- Keep drinking plenty of fluids and avoid excessive alcohol.

After a venesection, the body uses Vitamin B12, folate, iron and protein to manufacture new blood. People undergoing frequent venesections during the initial de-ironing phase of

treatment may find Vitamin B12 and folate supplements helpful to boost the ability of the body to make new blood cells. Talk to your pharmacist or GP about it, or read this article on our website for more information www.ha.org.au/dietvtx.

Access to Venesection

The procedure is not always the only problem though. The need for frequent venesections can also pose severe financial and lifestyle challenges for some: A member writes:

We work on a station over 200 km from anywhere. I have to travel for venesections to a non-bulk-billing clinic which elevates all the costs. We estimate \$450 a time – more if I have to stay overnight. So a recovery to workable levels will be slower. Very frustrating.

56 year old female member.
Serum Ferritin level 1310.
C282Y homozygous.

RESEARCH STUDY PARTICIPATION OPPORTUNITIES

Mi-Iron Melbourne or Brisbane

You may be able to help this study into the effects of reducing moderate iron overload if you:

- are c282y homozygous
- have moderate iron overload (SF 300 – 1,000 µg/L)
- are otherwise healthy
- have not had a venesection for the past 2 years
- live near Melbourne or Brisbane

More info at:

- <http://www.mcri.edu.au/research/research-projects/mi-iron-study/>
- Or call Lara 03 9496 4335.

Cost of Haemochromatosis Online Survey



How much does haemochromatosis cost an individual in terms of health costs, productivity and well-being? How much does haemochromatosis cost the Australian health system and society in general? Would you like to help find the answer?

More info <http://ha.org.au/survey-cost-of-haemochromatosis/> or contact Barbara de Graaff on (03) 6226 7479.

Factors Affecting Self-Management of Haemochromatosis TOWNSVILLE / ONLINE

Jessica Pearce, a fifth year medical student at James Cook University, Townsville is conducting the above honours project. The study will consist of two phases – focus groups and later an online survey.

The next focus group will be Tuesday 30 September at 7pm at Aitkenvale library, Townsville.

If you would like to participate contact Jessica at email jessica.pearce1@my.jcu.edu.au, or telephone (07) 4781 4474.

FGF23 Western Sydney / Blue Mtns



The research team are seeking men aged 35 years or over to participate in a study to look at Fibroblast Growth Factor 23, a blood marker of bone metabolism and its association with body iron stores.

Participating in the study involves:

1. Giving a single fasting blood sample
 2. Providing a single fasting urine specimen
 3. Having a check of bone density and body composition by an X-ray technique called DEXA
 4. Having a check of your weight
- Participating will involve 1- 2 visits for a total of up to 2 hours.

If you are interested, contact :
Associate Professor Emily Hibbert
Tel : (02) 4734 3294 or
emily.hibbert@sydney.edu.au

More information at:
www.ha.org.au/nepean

Properties of Red Blood Cells from Patients with Iron Overload Gold Coast

Researchers from the Griffiths University School of Medical Science are seeking volunteers.

Non-smoker male or female aged 35 years or older

- AND healthy with no history of red blood cell disease, bleeding disorder or thrombosis and currently not on any medication
- OR You have Haemochromatosis and have regular venesections as part of treatment.

You will be asked to:

- Give a blood sample at your next venesection appointment if you are undergoing venesections.
- Give a blood sample at the university if you are healthy and wish to volunteer.

Contact Dr Indu Singh
i.singh@griffith.edu.au
07 55529821
Or Ms Janelle Guerrero
janelle.guerrero@griffithuni.edu.au
0466 691557



Jessica needs your help

Forgotten something?



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1300 019 028**

HAEMOCHROMATOSIS: ONE STORY

About nine years ago I was settling happily into retirement after my wife and I had sold the country pharmacy business we had run for nearly 30 years. I had a vague memory of being told not long before we bought the business that my father had to have blood taken as he had too much iron. I had heard about haemochromatosis but pharmacists aren't usually involved in the treatment so thought maybe I'd better find out whether I had it.

My son's girlfriend gave me a print-out from a medical site which listed typical symptoms including fatigue, but though I'd never been a bundle of energy I didn't think that applied to me. It didn't seem to have affected Dad either as he loved nothing more than a long walk, was always up early and hated sitting round the place! In his earlier days he had been active in surf life saving and had won the NZ long distance swimming title. While in his 70s he had returned to competitive pool swimming and rewritten the record book in his age group. Joint pain wasn't a problem for us either. We enjoyed quite good health but I had discovered a leaking heart valve 30 years before. My heart rhythm was all over the place. The leak wasn't too bad and I had yearly check-ups.

I spoke to my GP who ordered iron studies and there it was – ferritin 1400 µg/l and transferrin saturation 100%. Gene studies showed homozygous C282Y. I was the one in 200. My siblings and sons are not affected for which I'm grateful. I was referred to a gastroenterologist who ordered liver tests which fortunately were clear. He referred me to the Red Cross Blood Service for regular venesections. They first wanted the OK from my cardiologist. Once they had that I went weekly for six months, until my ferritin was down to about 50.

I began maintenance venesections every three months. A couple of years on I was finding the effort required to keep our eight acre bush block safe during summer was getting too much for me so we looked to downsize. We eventually found an older house on a level quarter acre (very different!) and decided to gut it and do a complete renovation. We had tradesmen doing the tricky stuff while I did the labouring and my wife worked getting the garden (her passion) into the shape. After six months of hard work we moved in, both about 5kg lighter. Unfortunately I think the work had its downside. At my next regular heart check-up I was told 'Your valve has deteriorated, it will need to be repaired at some stage. Let me know if you get breathless'. A couple of weeks later I was getting breathless after moderate exertion so soon I was heading off to Melbourne for surgery, but rang ahead to explain about my haemochromatosis and ask should I have the venesection that was due. The surgeon replied 'Don't worry, we'll take plenty out of you!'

I was told that some people return from a valve repair jumping out of their skins, while others look as though they'd been run over by a truck. I was somewhere in the middle. I wasn't much use for anything for a while. Gradually things settled down. I had a very good report on the repair, but I was still unhappy about feeling tired a lot of the time although it came and went to a certain extent. Eventually I started having venesections again every six months, but now Red Cross wouldn't touch me because of my surgery as they don't have a doctor on site. I went to Ambulatory Care at the Royal Hobart Hospital which was no burden.

Late last year I saw my GP on another matter but started off by saying that I was fed up with feeling

tired all the time. He ordered a battery of tests, none of which showed anything. In the New Year I was getting worse. I would have a good day and think I was making progress, then next day or two I'd be laid low recovering. Frequently I'd go for a walk and by the time I got home I could hardly drag one foot after the other, while hour-long sleeps after lunch became more common. Eventually I started to wonder if I should try lowering my iron levels more. The latest test had my ferritin at about 125, well within limits as far as organ damage was concerned, but I decided to follow this up so brought forward my next scheduled venesection. I saw my specialist before the venesection and explained my thoughts, to be told that there was 'no obvious need for it, but I do have another patient who keeps having venesections because he feels better after them, so go ahead and let me know how you feel'.

The turn-around was nothing short of amazing. Two days after the venesection, I spent an hour steam-cleaning carpets in a unit we own. A week before I doubt I would have lasted ten minutes. Of course my iron levels would again increase, so as a precaution I booked another venesection after six weeks and was very glad I did as a week before it was due I started to feel weary again, exemplified by a short walk I had great difficulty finishing. Once again matters improved after the venesection and I have now moved to an eight week schedule of venesections but I'll keep that under review of course. I now have mild cardiomyopathy which was probably caused by iron, but it's good to feel well and able to do things again. The moral of the story is take an interest in your own treatment and don't be afraid to ask questions!

Peter Hepburn, Clairemont, Tas.

DOUBLE OVERLOAD

This year the OVERLOAD exhibition which helps raise awareness of haemochromatosis and funds for our association was held in both Hobart and later Launceston.

Thanks to Sarah Weaver, curator and artist, who has organised a magnificent event three years running. Many of the contributing artists have a personal connection with haemochromatosis. This year the exhibition sold 15 artworks with commission donated to our society. Hundreds of people have viewed the exhibition and read the artists personal observations on 'overload'.



Ben thanks Sarah for her hard work, dedication and creativity.

Thanks also to Sheila Stevenson who helped organise the Launceston exhibition, Cooleys Hotel & The Stable Gallery Hobart, ARTtrium Gallery Launceston, Southern Cross Austereo, Dean Stevenson, the artists, helpers and our generous sponsors including Launceston Pathology, Rebekah Lodge, Just Frames, Elly's, Sew & Sow, L.U.S.T., Bruny Island Cheeses, Elise Archer MP, Matthew Dames, Josef Chromy, Petrarchs, and Red Ted's Tavern.

AROUND THE NATION

There's been lots happening around the country since last newsletter.

Perth started early with a gathering at Sir Charles Gairdner Hospital on June 26. Vice-President Desma flew over from Adelaide to help local volunteers led by Kristy host the session. About 15 people participated with many agreeing to help out with awareness raising in the future. Desma also addressed an education day for 120 gastroenterology nurses while in, Perth. If you live in WA and would like to help contact Kristy email kristy_083@hotmail.com or call 0407 985211.

Sheryl and Tom Brannan from **Townsville** were busy with displays at the Townsville information Centre, Senior's Expo, James Cook Uni and more. The Townsville Haemochromatosis Support Group meets monthly. Contact Sheryl email tom.brannan@bigpond.com or call 07 4725 3973.

In regional Victoria, local volunteer advocate Judi McDonald and Benalla Community Health Nurse Deb Smith organised a meeting in **Benalla**. They managed to drum up lots of publicity with print, radio and TV interviews and lots of posters around the region. President Ben Marris attended to give a presentation to about 30 locals and visitors. Ben also addressed the nursing staff at Shepparton Red Cross Blood Donor Centre.

On the **Sunshine Coast**, over 30 people braved a tropical downpour to attend an information session at Maroochydore presented by committee members and locals Tony Moorhead and Linda Rule.

Canberra held an information session 2 September with Dr Mark Bassett, a local gastroenterologist presenting a well received talk on haemochromatosis to a packed house of over 60 attendees. President Ben Marris rushed from a meeting with Assistant Health Minister Fiona Nash at Parliament House to join the meeting to tell the attendees about the work of Haemochromatosis Australia. Maree Sullivan is the local volunteer looking for anyone interested in

helping raise awareness in the ACT - email marees@grapevine.com.au or call 0415 501626.

Hobart saw the launch of Awareness Week, our AGM and an information session on 9 August. About 40 people attended. Visiting and local members of the management committee took the opportunity to get together for an extra day conference and a visit to the OVERLOAD art exhibition. Thanks Jon Hortle and local volunteers who helped make the event such a success and made everyone welcome.

Launceston and northern Tasmania didn't miss out with Sheila Stevenson leading the effort there with several talks, displays and the OVERLOAD art exhibition.



Sheila at Kings Meadow

The **Blue Mountains** discussion group meets monthly with the next meeting scheduled for Blackheath on 8 October.

Email: barbara@ozemail.com.au or phone 02 4787 7937.

A small group also meets regularly in **Adelaide**. The next meeting has not been scheduled yet but keep an eye on the Meetings page of our website or call the INFO LINE if you would like to find out more.

Rounding out the list was **Toowoomba** in Queensland with the usual informal meeting at Cheryl Wilson's home. The next Toowoomba group meeting will be 8 March 2015. Contact Cheryl on 07 4635 6275.

There were lots of other events and happenings too numerous to mention around the Awareness Week. Thanks everyone who played a part – large or small. It all makes a difference.



Sadly we report the passing of Mr Evan Kemp of Kambah, ACT and Mr Noel Forster of Toowoomba, QLD.

Our condolences and thanks to the families who requested donations to Haemochromatosis Australia in lieu of flowers.

Thanks also to:

- Nikky Kozubek and *Mummies Little Helpers* of Ipswich who raised funds in memory of her uncle Billy Wright
- Launceston Pathology
- Rebekah Lodge
- and especially to all of our members who have made donations with their membership subscriptions.

In 2013-2014 we received \$13,600 in donations, almost a quarter of our non-grant income for the year.

Thank you all.

You can help us share in \$1 Million for charity!

Dick Smith Foods are giving \$1 Million to charities this year. With your help, Haemochromatosis Australia could receive a donation of \$10,000, \$20,000 or even \$50,000. That will go a long way to help us raise awareness and promote early detection.

Simply **text or email a photograph** of any Dick Smith Foods product in your pantry to: **charity@dicksmithfoods.com.au** and name **Haemochromatosis Australia** as your charity.

The charities with the most votes will share in \$1 million. With your help we could be one of those charities. More info at <http://www.dicksmithfoods.com.au/charity-breakthrough>



Entertainment Membership

Haemochromatosis Australia are now raising funds with the familiar Entertainment Book and the new digital membership for all major capital cities. Profits from the sale of Entertainment memberships will be used to help fund our Haemochromatosis INFO LINE 1300 019 028 and to purchase new resources to help us raise awareness and promote early detection and treatment.

There's over \$20,000 value for just \$65 for either your local book or the handy new smartphone version. Discover hundreds of valuable offers (up to 50% off and 2-for-1) for many of the best restaurants, arts, attractions, hotels, travel, shopping and much, much more!

Purchase your book or digital membership at <https://www.entertainmentbook.com.au/orderbooks/91259h5>. 20% of the purchase price is donated to help us achieve our mission.

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Contact Us

Haemochromatosis Australia

We are a not for profit support and advocacy group run entirely by volunteers.

Find out more, join us or donate at our website www.ha.org.au

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