





## About Haemochromatosis Australia

Haemochromatosis Australia is the support and advocacy group for people affected by hereditary haemochromatosis.

**Mission:** To provide support and promote awareness, early detection and research.

**Vision:** No Australian will suffer harm from haemochromatosis.

**We believe that people with haemochromatosis are entitled to:**

- the same quality of life and life expectancy as other Australians
- diagnosis before symptoms occur
- well informed health and medical services
- easy access to the knowledge, support and services they need.

“No one need suffer harm from haemochromatosis”



 haemochromatosis

 @HaemAus

 Haemochromatosis Australia

 HaemochromatosisAust

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 **Haemochromatosis Australia**  
Inherited Iron overload disorder

**Front cover: Tommy Boyce**  
**Back cover Tony Moorhead**

# President's report – Dr Dianne Prince

This report highlights Haemochromatosis Australia's (HA) achievements over the past 12 months, achievements only possible through the continuing determination and dedication of past and present members of the committee and volunteer advocates, and the support of our advisory panel of eminent researchers and clinicians.

Firstly I would like to acknowledge the wonderful generosity of everyone involved in the work of Haemochromatosis Australia. We are still a completely volunteer organisation, which surprises many when they hear about the way we work and what we have achieved over the years since Marg Rankin first set up the group. We are very fortunate to have a strong management team with complementary skills and experience. To quote my predecessor Ben Marris 'the best teams are made, not of people all the same, but people with a range of attributes'. We are also very lucky to be able to rely on world class advice and clinical direction from our scientific and medical advisors.

We welcome Dr Barbara De Graaff (UTAS) and Jayne Hunt to the management committee and Dr Peter Bentley of Australian Red Cross LifeBlood to our board of Scientific and Medical Advisors. Barbara's research on the health economic aspects of hereditary haemochromatosis, which included the first quantification of the economic burden associated with haemochromatosis, provides essential support for the case for early diagnosis and treatment. Jayne joined us after recently settling in Australia from the UK, bringing her experience as an active volunteer for Haemochromatosis UK and her professional background in marketing to the mix. Peter was instrumental in designing and implementing the High Ferritin App used by GPs to refer patients as Therapeutic Donors and is involved in haemochromatosis research.

Three individuals in particular deserve special recognition for their contributions as members of the management committee. Desma Wieringa retired from her role as HA vice-president and committee member at the 2019 AGM, having served in this position since 2009. Years prior to joining the committee, Desma started a support group in South Australia which continues today.

Desma, a highly qualified nurse and nurse educator, has worked tirelessly to raise awareness of haemochromatosis not only among the general public but also very importantly with nurses. Last year her determination was rewarded when APNA, the Australian Practice Nurses Association, published an accredited online module on haemochromatosis and venesections for practice nurses. This is a wonderful example of HA's work supporting health care professionals who treat people with haemochromatosis.

Desma has also been the mainstay of our InfoLine providing advice and counselling for newly diagnosed people or their family members seeking help and information. We thank Desma for her great generosity in sharing her experience and wisdom over many years. Desma intends to remain involved as a Volunteer Advocate.

The second person I would like to acknowledge and thank is James Stephenson who retired from the committee at the end

of June this year. In his non HA life James is an architect with a passion for Japan and small houses. James organises and leads tours to Japan in addition to designing buildings!

Finally I would like to recognise the extraordinary contributions of HA secretary Tony Moorhead who has clocked up 10 years of service in that role. Fortunately for us he isn't stepping down! In the words of past president Ben Marris - 'Tony's the engine room of HA. Over the last ten years other people have joined the core of HA and some have moved on. Many people have done great work to make the organisation the huge success that it is. But Tony has been central. We were all useful but Tony was essential. He brought his business process and administrative skills to become the axle on which we all turned. He guided us gently to put the systems in place and get the job done. He has never wavered in his enthusiasm, his readiness to adopt new ideas, and his ability to just make things happen. And he has done it all with a smile.'

HA's vision that no Australian suffers harm from haemochromatosis was given a boost in this past year with funding from the Federal Government under the Department of Health's Chronic Disease Prevention program for an awareness campaign targeting young people.

The success of this campaign is largely due to the wonderful efforts of Elizabeth McCray who worked with production teams to get the materials created, managing social media posts and traditional media releases and stories. As part of the project we were able to get a new Community Service Ad (CSA) produced, featuring James and Anne Barclay. The CSA is currently being shown on regional television around Australia. In addition we were able to run it and an animated video in selected doctors' surgeries which were also supplied with HA brochures. This activity further strengthened HA's support for the development of Haemochromatosis HealthPathways in Primary Health Networks. Karin Calford's determined commitment to developing strong relationships with Primary Health Networks, and her advocacy for HealthPathways, has seen 18 Primary Health Networks develop them already with more underway.

I am very happy to report that we secured another grant this year, this time to develop education materials for GPs and healthcare professionals. Work has started on the production of videos, podcasts and an online learning program on haemochromatosis to be rolled out in April 2020.

Once again we would like to thank our generous donors. In addition to the smaller donations sometimes paid when people renew their membership we have been very fortunate to receive a couple of larger amounts. These enable us to plan for activities such as our conference and Information Sessions (three this year in Adelaide, Melbourne and Perth), as well as attendance and displays at conferences for healthcare professionals. Without these generous donations we would not be able to undertake these types of valuable face-to-face activities.

We ask for your continuing support to help us achieve our goal of ensuring no-one is harmed by haemochromatosis.

# Support for people with haemochromatosis

Haemochromatosis Australia provides support and promotes awareness, early detection and research across a range of different media. Support for individuals is aimed at enabling management in consultation with medical professionals. All medical information is reviewed and approved by our medical and scientific advisors.



## InfoLine – 1300 019 028

- Provides free information to all callers independent of membership status.
- Five committee members volunteer to staff the information line during office hours.
- 2018/19 – 601 calls received.
- 2017/18 – 710 calls received.
- 2016/17 – 605 calls received.

## Information for new members

- Family letter explaining what family members need to know about this inherited disorder.
- Two information sheets are provided to new members:
  - *Genetic Test Results and Haemochromatosis Mutations.*
  - *Diet and Haemochromatosis.*
  - *Preparing to give blood: Tips for a successful venesection.*

## Social media

- Facebook page is popular with 5944 Likes. This is an increase of 1591 Likes for the year. Since Feb 2019 there have been 26,469 engagements.
- 751 Twitter Followers via @HaemAus. This is an increase of 127 Followers for the year. Since Feb 2019 there have been 975 engagements.
- Instagram Followers are increasing with 299 Followers for the year. Since Feb 2019 there have been 3197 engagements.

## Venesection record book

- An updated venesection record book was produced. These books are sent to all new members and provided free of charge to venesection providers and members of the public on request..

## Practical Guide to Haemochromatosis

- This book, first published in 1981 is undergoing a comprehensive update for publication in print and digital forms.

## Iron Age News

- *Iron Age News* is emailed or posted to members each quarter. The newsletter provides useful information and tips about iron overload and its management, latest research news, Haemochromatosis Australia activities and events and stories from our members.

## Video package on YouTube

- HA makes available a series of information and patient experience videos on our YouTube channel, Facebook page and website.
- 2-minute animated Haemochromatosis and 10-minute Haemochromatosis Explained videos remain extremely popular with over 60,000 and 10,000 combined views respectively.
- 2018/19 featured a new series of patient experience and expert videos during our social media campaign. These received approximately 75,000 views during the campaign.
- All videos remain available to view on internet and social media channels and are proving very valuable tools to provide information, support and raise awareness in the online environment.

## Website – [ha.org.au](http://ha.org.au)

- Delivers information and support to the general public and health professionals.
- 615,029 page views from 149,057 unique visitors.

## Haemochromatosis:

### Your questions answered (HYQA)

- The HYQA booklet is accepted as the principal patient information document on haemochromatosis in Australia.
- It is distributed free-of-charge to individuals, organisations and clinics.
- 2018/19 approximately 3000 copies were distributed.

## Australian Red Cross Lifeblood team

- 2018/19 Haemochromatosis Australia state-based Lifeblood team results (formerly RED25).

Organisation Name	Whole Blood	Plasma	Lives Saved
HA – NSW	353	18	1113
HA – QLD	363	1	1092
HA – SA	145	0	435
HA – TAS	129	9	414
HA – VIC	44	4	144
HA – WA	15	5	60
HA – NT	0	0	0
HA – ACT	62	0	186
<b>National Total</b>	<b>1111</b>	<b>37</b>	<b>3444</b>

# Raising community awareness

## July 2018 – CWA AGM Peachester

- Tony Moorhead addressed the Annual General Meeting of the Peachester branch of the Queensland Country Women's Association about haemochromatosis.

## 14-15 July 2018 – Man Cave Expo

- Display at Man Cave Expo at Sydney Olympic Park.

## 18 July 2018 – Radio interview

- Dr Dan Johnstone, neuroscientist and senior lecturer at the University of Sydney as well as HA management committee member spoke on ABC Nightlife with Philip Clark.
- <http://www.abc.net.au/radio/programs/nightlife/dan-johnstone/10182836>

## U3A Seniors Expo – 22 August 2018

- Display at Toowoomba U3A Seniors Expo.

## 28 November 2018 – Benalla Disability and Seniors Expo

- Display at Benalla Disability and Seniors Expo.

## November 2018 – Thank-you event for Patient Partner program at University of Tasmania

- Volunteer Advocate Sheila Stevenson is part of this program that aims to engage community patients with undergraduate medical students in learning partnerships.

## March 2019

- HA committee member, Matthew Howie met with Ms Nicolle Flint MP to discuss haemochromatosis.

## 16-17 March 2019

- HA committee planning weekend was held in Sydney.

## 19 March 2019

- HA vice president, Desma Wieringa spoke at Rotary Club of Strathalbyn, South Australia.

**Haemochromatosis Australia (HA) would like to thank all Volunteer Advocates. HA is an entirely voluntary, not-for-profit organisation and could not run without their assistance.**

**Volunteer Advocates make a most important contribution by carrying out activities in communities all around the nation.**

## 3 April 2019

- HA volunteer advocate, Judi McDonald was interviewed by Peter Dunbabin for radio station *One FM Shepparton* about all things haemochromatosis.

## 3-9 June World Haemochromatosis Week 2019

- Community Service Announcement ran on a variety of radio stations.
- 14 radio interviews.
- Four regional television news stories.
- Various articles in both print and online newspapers.
- Social media posts from aligned organisations, politicians, members, medical practices and the general public.
- Members ran information tables in shopping centres.

## Overload art exhibition 2019

- Overload 2019 opened during World Haemochromatosis Week at Deloraine Hospital Gallery and ran until 9 November 2019.

## 15 June 2019 – Adelaide Information Session

- 60 people attended.
- HA vice-president Desma Wieringa spoke about haemochromatosis generally.
- Dr Jackie Coughlin, Australian Red Cross Lifeblood spoke about their therapeutic donor service.
- Question and Answer session moderated by Matthew Howie.



# Australasian Haemochromatosis Conference

Haemochromatosis Australia's 3<sup>rd</sup> Biennial Australasian Haemochromatosis Conference was held 25-26 August 2018 in Newcastle.

It provided a great opportunity for patients, researchers, nurses and clinicians to share the latest information on detecting haemochromatosis and preventing iron overload. The theme of the conference was 'Detection and Prevention: a future without iron overload'.

- Attendees from New Zealand and all Australian states and territories (except Northern Territory)
- Majority of sessions involved mix of patient, nurse, doctor, scientist and student enabling each group to learn from the other and share their varied viewpoints
- Keynote speaker UON Laureate Professor Rodney Scott, a world-renowned expert on genetic research and personalised medicine
- Concurrent research program
- Venesection workshop for nurses
- Varied mix of presentations, discussion and question and answer sessions
- Haemochromatosis Australia's **Red25** Blood Donation Challenge launched

## Conclusions

### Is a future without iron overload possible?

- **Yes** – if those at risk with the genetic predisposition for overload are detected and treated early, symptoms can be prevented easily
- Already have a simple gene specific test for most common mutations
- Advances in genomic scanning techniques and equipment are rapidly improving the chances of detecting risk
- Treatment with venesection is simple, effective and cheap
- Research progressing gradually toward alternative treatments for the small proportion of people who do not tolerate venesection well
- Beginning to understand factors that cause overload outside the common known risk factors
- Beginning to understand the biology and chemistry of iron metabolism better and how too much iron harms the body
- Great advances in raising awareness of the condition within the community and health professions so that those at risk will be detected routinely before harm occurs



# 2019 Social Media Campaign — *Is your iron right?*

- Launched February 2019 at University of Sydney
- Three month campaign ending with World Haemochromatosis Week
- Funded by Department of Health grant under the Public Health and Chronic Disease program
- Healthily, a Melbourne based health communications company, developed and recorded interviews with patients who generously gave up time to tell their stories of being diagnosed and living with haemochromatosis
- Short edited videos were shown on Facebook with longer versions posted on our YouTube channel
- Graphics, 'Did you know' questions and animated jingle were also developed for Facebook, Instagram and Twitter
- Production of community service announcement for television which was shown on regional channels and in selected medical practices
- Increased media interest with interviews on television, radio and in print with stories published in newspapers and magazines.

## Key messages

- **Tricky to say**
- **Easy to test**
- **Simple to treat**
- **Tragic to ignore**

## Call to action

**'talk to your GP about haemochromatosis and get tested'**

## Campaign aims

### Young adults at risk of iron overload will

- **understand hereditary haemochromatosis and risks associated with iron overload**
- **know how to self-manage the condition**
- **become regular blood donors and have therapeutic venesections as required**
- **monitor iron levels for life**

## Campaign results

- **Monitoring social media responses, counting the increase in number of likes, followers and shares demonstrated more people are now aware of haemochromatosis**
- **A number of other health organisations shared posts including Cancer Council, Heart Foundation, Arthritis, Diabetes groups**
- **Primary Health Networks communicated key messages**
- **Comments on posts indicated more young adults at risk of iron overload understand hereditary haemochromatosis and the dangers associated with iron overload, become regular blood donors and have therapeutic venesections as required**
- **increased membership of our Australian Red Cross Lifeblood team**
- **Established relationships with health groups**



# Professional engagement and research

One of the objectives of Haemochromatosis Australia (HA) is to influence and advocate health policy relating to haemochromatosis. We encourage research that contributes to achieving our vision that no Australian suffers harm from haemochromatosis.

In 2018/19 committee members participated in conferences to increase awareness, shared knowledge and learnt about current research. Where possible HA provides support for relevant research.

## August 2018

New haemochromatosis HealthPathway Wide Bay.

## 22 August 2018 – Genetic Alliance Australia Leadership Meeting: Tour of the Kinghorn Cancer Centre laboratories and talks with scientists

- President, Di Prince attended this meeting and tour. Grateful thanks to Bronwyn Terrill, Garvan Institute of Medical Research, for hosting the tour and helping explain the broad picture of genetic testing and research.
- Di gained an understanding of costs of testing and research, and the potential for analysis in the near future. There was an opportunity to speak with the scientists and chat about research parameters and practical applications for those affected by genetic conditions including haemochromatosis.

## 4 September 2018 – Visit to Garran Donor Centre

- Inservice staff training by Volunteer Advocate Karin Calford at Lifeblood Garran Donor Centre.

## 19 September 2018 – Visit to Maroochydore Donor Centre

- Inservice staff training by Committee member Tony Moorhead at Lifeblood Maroochydore Donor Centre.

## 17 October 2018 – Visit to Springwood Donor Centre

- Inservice staff training by Committee members Tony Moorhead and Elizabeth McCray at Lifeblood Springwood Donor Centre.

## 21-24 October 2018 – Blood 2018

- Information booth at *Blood 2018* - the combined Annual Scientific Meeting of the Haematology Society of Australia and New Zealand, Australian and New Zealand Society of Blood Transfusion and Thrombosis and Haemostasis Society of Australia and New Zealand.

## 26 October 2018 – Visit to Goulburn Donor Centre

- Inservice staff training by Volunteer Advocate Karin Calford at Lifeblood Goulburn Donor Centre.

## November 2018

- Haemochromatosis HealthPathway Western Australia.
- Haemochromatosis Australia article in Tasmanian PHN *Primary Health Matters* magazine.
- Volunteer Advocate, Karin Calford attended ACT Health Care Consumers Association conference.

## 21 November 2018 – Visit to Chermiside Donor Centre

- Inservice staff training by Committee member Tony Moorhead at Lifeblood Chermiside Donor Centre.

## 27 February 2019

- HA president, Dianne Prince met with Andrew Mills, CEO, Arthritis Australia to discuss haemochromatosis and arthritis.

## 24–27 March 2019

- Information booth at the 15<sup>th</sup> National Rural Health Conference held in Hobart.

## 4–6 April 2019

- Information booth at Australian Primary Health Care Nurses Association (APNA) Conference held in Adelaide.

## May 2019

- May 2019 Haemochromatosis Australia powerpoint 'Therapeutic Donors: Inherited Iron Overload' placed in Australian Red Cross Lifeblood resources for National Donor Care staff.

## 2018/19 – Australian Red Cross Lifeblood High Ferritin app

- 8.4 percent increase in number of people with haemochromatosis referred via High Ferritin app as therapeutic donors.
- 8.2 percent increase in C282Y homozygotes.
- 8.6 percent increase in C282Y/H63D compound heterozygotes.

### Interesting fact

Haemochromatosis is a keyword used by Australian consumers in Google 9900 times per month on average. In terms of Haemochromatosis' rank among medical conditions for which General Practice Supervisors Australia (GPSA) has a teaching plan it is ranked second.

In terms of downloads, the haemochromatosis resource has been downloaded 1616 times since it was first published and is the eighth most downloaded teaching resource used by GP Supervisor visitors to the GPSA website.

# International Haemochromatosis Patient's Meeting

The International Haemochromatosis Patients' meeting was held 10 May, 2019 in Heidelberg Germany.

It was a great success with 51 people – representatives of patient organisations, leading clinicians and researchers attending, including Australians Prof Greg Anderson QIMR (member of Haemochromatosis Australia Advisory Group), Prof Liz Milward and Seak Lin Ly (iron researchers from University of Newcastle).

This meeting is held every two years immediately following the BioIron conference.

Dr Dianne Prince, was elected incoming president of Haemochromatosis International at this time. Dianne replaces Prof Paulo Santos (Brazil) as president and follows on from past president Mr Ben Marris, (Australia). She continues in her role as Haemochromatosis Australia president.

This international alliance of volunteer haemochromatosis organisations enables us to work together to expand knowledge and awareness about the condition around the globe.

Haemochromatosis International member organisations have successfully lobbied their national governments for action in relation to treating haemochromatosis.

Closer relationships have been established with the blood banks in some countries and clinicians have access to Therapeutic Recommendations in several languages, as well as to patient resources via workshops and online health pathways.

Member organisations include haemochromatosis groups from Australia, Belgium, Brazil, Canada, Europe, France, Germany, Hungary, Ireland, Italy, Norway, Poland, Portugal, Spain, United Kingdom and United States of America.



## Proposed projects include:

- mounting a campaign for free access for all haemochromatosis patients in the world to phlebotomy (venesections).
- establishing a register of all haemochromatosis patients detailing genetics, symptoms, complications, biochemical levels and other diseases.
- setting up a library or clearing house of published scientific and clinical research.
- investigating unmet needs in H63D homozygous patient populations, C282Y/H63D compound heterozygote patient populations and in Asian populations. For example UK Pakistani young men.

## Our patrons and eminent professional advisors

**Haemochromatosis Australia is very fortunate to have a panel of esteemed and eminent professional advisors providing guidance and advice.**

**Margaret Rankin AM RN GradDipHthSc, Patron**  
Marg was appointed Patron in 2010. She was our founding president and retained that office for over 20 years until she stepped down in 2010. Marg remained an active member of the management committee until the 2013 AGM. She is highly respected in haemochromatosis matters in Australia and overseas. Her contribution to haemochromatosis support was recognised with a Member of the Order of Australia (AM) medal in 2005. Marg lives in Brisbane, Queensland.

**Professor Emeritus Lawrie Powell AC, Patron and medical advisor**  
Emeritus Professor, UQ Centre for Clinical Research, The University of Queensland, Brisbane, Queensland

### **Dr Katie Goot**

Rural GP based in Central Queensland

### **Professor John K. Olynyk**

Head of Gastroenterology, Fiona Stanley and Fremantle Hospital Group, Western Australia

### **Professor Martin Delatycki**

Medical Director, Victorian Clinical Genetics Services, Director, Bruce Lefroy Centre for Genetic Health Research, Murdoch Children's Research Institute, Melbourne, Victoria

### **Dr Peter Bentley**

Senior Medical Officer, DPU, Australian Red Cross Lifeblood

### **Professor Darrell Crawford**

Head, Mayne Professor and Head, Discipline of Medicine, The University of Queensland, Brisbane, Queensland

### **Professor Greg Anderson**

Co-ordinator, Chronic Disorders Program, Head, Iron Metabolism Laboratory, QIMR Berghofer Medical Research Institute, Brisbane, Queensland

# Management committee



Dr Dianne Prince  
DBA, MEd, BA

**Dianne Prince**, *president*, became a Volunteer Advocate in September 2014 and was elected president in August 2016, bringing public and private sector management experience from the fields of education and business. Before retiring she worked for 20 years in the pharmaceutical industry in operations and supply chain management. Di was awarded a DBA for her research on Health Consumer Organisations.



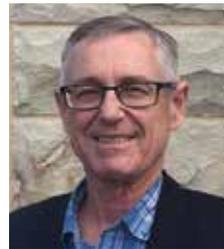
Tony Moorhead

**Tony Moorhead**, has been *secretary* of the association since 2010. He is a retired federal public servant with extensive experience in project management, marketing and communication, business analysis and organisation development. Tony is responsible for the business and administration of the organisation and plays a key role in marketing and communication and technology. He lives in Currimundi, Queensland where he is also active with other community groups.



Desma Wieringa  
RN RM, BN

**Desma Wieringa**, *vice-president*, has served on the management committee over the past 18 years with a break of one year, 11 years ago. Desma has previous experience in managing and providing support in a Womens' Midlife Information Service in Tasmania for a period of four years. Desma has worked as a Midwife, Registered Nurse and as an educator in the Enrolled Nurse program at TAFESA. She is now retired.



Matthew Howie  
B Fin Admin, Grad  
Dip Conflict Mgt

**Matthew Howie**, *committee member*, Diagnosed in 2007, as a result of arthritis of the hands, Matthew joined Haemochromatosis Australia in 2008. He has been a volunteer advocate in Adelaide since 2014 after attending the Melbourne Conference. Matthew is currently employed part-time as a relationship educator. Previous employment has included middle-level management in several Commonwealth Departments in SA and NT and more recently as a Family Mediator in an NGO. Matthew is also a Life Member of the Unley Apex Club.



Dr Barbara de Graaff  
PhD

**Dr Barbara de Graaff**, *committee member*, is a postdoctoral research fellow in health economics at the Menzies Institute for Medical Research, University of Tasmania. Barbara completed her PhD in 2016 on the health economic aspects of hemochromatosis. This involved assessing the quality of life and health economic aspects of the condition, and developing a disease simulation model to assess the cost-effectiveness of introducing a genetic population screening program in Australia. In addition, Barbara is a board member of the Australian Health Economics Society, a visiting scholar at the University of Melbourne and currently supervises five PhD students.



Dr Dan Johnstone  
PhD

**Dr Dan Johnstone**, *committee member*, is a medical research scientist based at the University of Sydney. Dan's PhD research focussed on iron overload, specifically the effects of haemochromatosis on molecular systems in the brain. In a strange twist of fate, he was incidentally diagnosed with haemochromatosis himself while in the midst of studying the condition. He continues to work on research projects relating to haemochromatosis and the central nervous system (brain and retina) with collaborators in Newcastle, Western Australia and Brisbane. Dan joined the management committee at the 2013 AGM, and is also the Immediate Past President of the Australian Society for Medical Research (ASMR).



James Stephenson  
FRAIA

**James Stephenson**, *treasurer*, is a practicing architect and business operator. He has been a Haemochromatosis Australia committee member since 2010. Previously he has participated in Royal Australian Institute of Architects and local parish committees. He lives in Brisbane, Queensland.



Elizabeth McCray  
BBus(Mgt)

**Elizabeth McCray**, *committee member*, joined the management committee of Haemochromatosis Australia at the 2017 AGM. Elizabeth assists with social media, publication of newsletters, and media releases. She has worked for various national and state based organisations in both administration and publications.

# Finance and membership 2018/19

The full financial accounts and audit report presented to the Annual General Meeting on 24 August 2019 is available on request to The Secretary, PO Box 6185 MERIDAN PLAINS QLD 4551 or [admin@ha.org.au](mailto:admin@ha.org.au)

## Balance sheet

The main asset of Haemochromatosis Australia (in financial terms) is cash, and a small amount of computer equipment. We changed from a cash accounting to an accruals accounting basis this year. We were registered for Goods and Services Tax in June 2019.

We had no debts apart from a small amount of accounts payable as at 30 June 2019. Combined cash in bank accounts at 30 June 2019 was \$478,678. This total included \$334,958 grant funding earmarked for projects to be undertaken during the 2019/2021 years. Of course our biggest asset is our members, volunteers (including Volunteer Advocates and committee members), and public goodwill.

### Assets

Cash at bank	\$478,678
Plant and equipment	\$614
GST paid	\$1,688
Deposit paid	\$7
<b>Total assets</b>	<b>\$480,967</b>

### Liabilities

Liabilities	\$275
GST collected	\$33,695
Grants received in advance	\$169,701
Total liabilities	\$230,671
Equity	\$277,296

## Profit and Loss

Income	\$265,615
Expenses	\$229,180
<b>Profit for year</b>	<b>\$36,435</b>

## Membership

At 30 June 2019 we had 835 financial members.

## Our organisation

Haemochromatosis Australia is an Incorporated Association under Queensland legislation. The Australian Taxation Office has endorsed us as a Deductible Gift Recipient. Gifts of \$2 or more are tax deductible.

We are registered with the Australian Charities and Not for Profit Commission as a registered charity ABN 79 827 140 617.

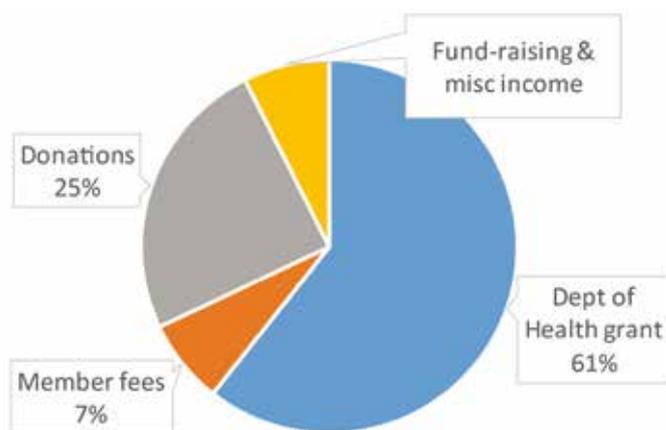


David Moorhead, Treasurer (2019/20)

## Income

Our regular source of income is member subscriptions and donations. We receive no recurring government funding for operational expenses or commercial sponsorship. In June 2019 we received a non-recurring grant of \$330,000 (GST Excl) from the Australian Government Department of Health under the Public Health and Chronic Disease Grant Program for a specific agreed project. The funds will be expended during the 2019/2020 and 2020/2021 financial years on that project. This was in addition to the grant received in the previous financial year which was fully expended during 2019.

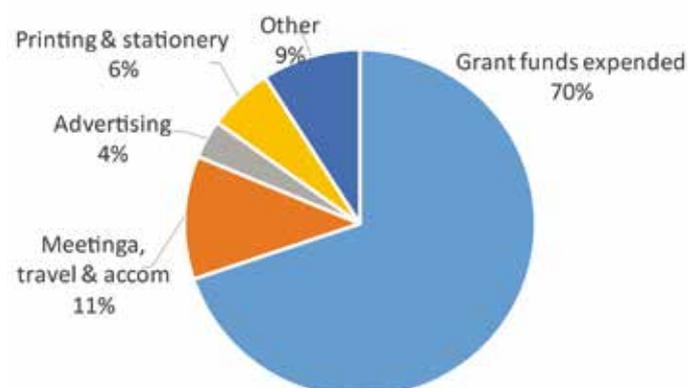
We undertake some minor fund-raising activities such as the OVERLOAD art exhibitions and sale of promotional jewellery. However as an all-volunteer group our main focus is support of members and raising awareness of haemochromatosis.

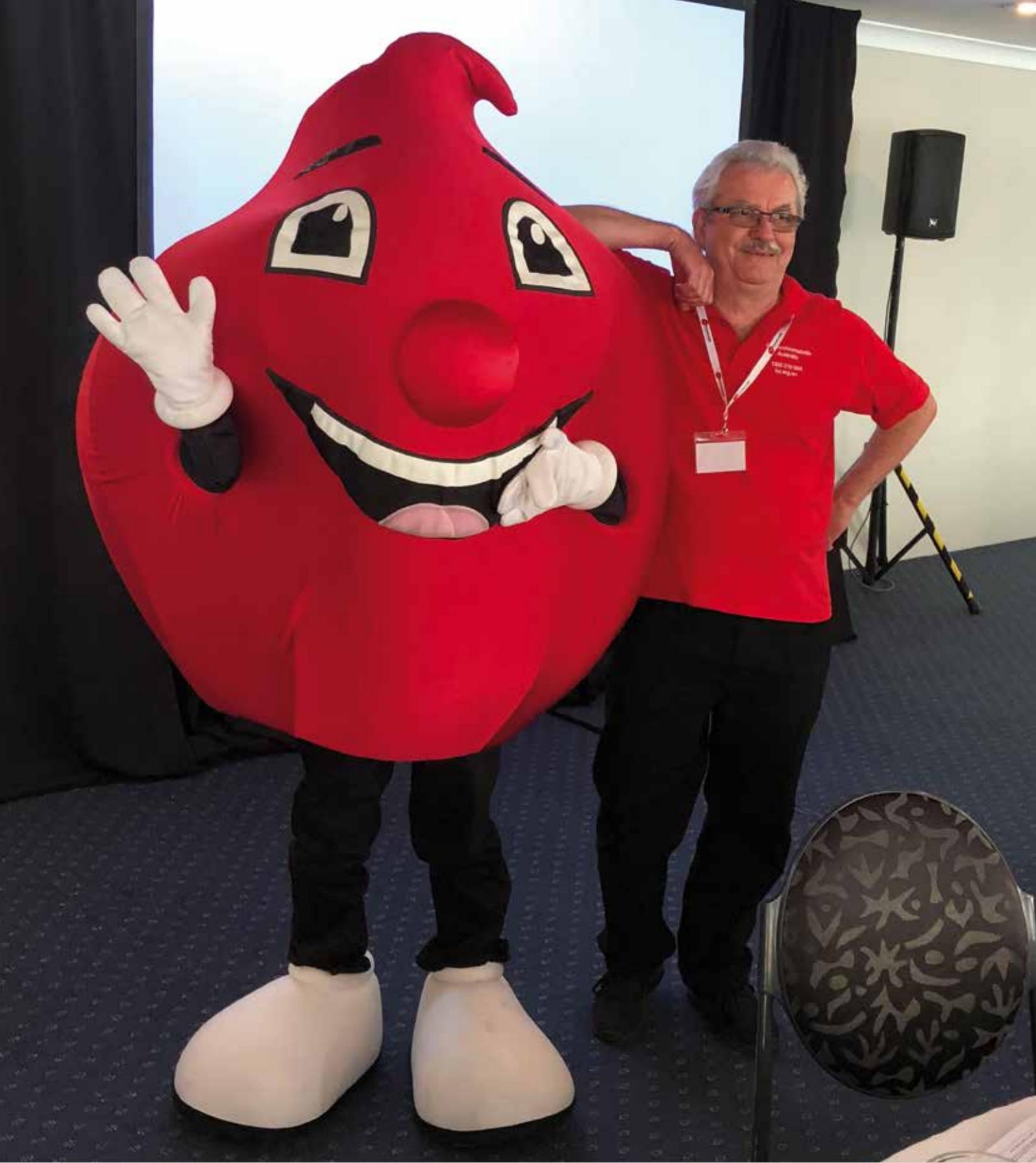


## Expenses

Haemochromatosis Australia is an all-volunteer organisation. We have no paid staff. Members of the management committee receive no remuneration apart from reimbursement of direct costs incurred.

We operate out of our homes and make use of technology donations and efficient business practices to keep overheads low.





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