

Patrons

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HAEMOCHROMATOSIS AUSTRALIA ANNUAL REPORT 2015/2016

The strategic vision of Haemochromatosis Australia is that
'No Australian will suffer harm from haemochromatosis'.

Our mission is to be the primary advocacy group for Australians affected by Haemochromatosis and to provide support and promote awareness, early detection and research.

We have grouped the activities of the organisation under the following headings -

- 1.Support people with Haemochromatosis
- 2.Community awareness
- 3.Professional awareness
- 4.Health policy improvement
- 5.Research
- 6.Society administration and governance

This report is under all six headings.

1.Support people with haemochromatosis

The essence of support is to give people good, concise and relevant information so that they can manage the condition themselves, in co-operation with their medical professionals. On occasion it is also important for people with haemochromatosis to feel that they are not alone and are able to discuss their situation with someone who understands.

HA provides information in a range of traditional and contemporary forms.

Web site - ha.org.au

The HA website is consistently at the top of the Google list when searching for information about haemochromatosis. This year the number of visits per month has increased to over 25,000 or 800 per day. This continues the rapid growth of the previous year. More details of the website analytics are below.

While the data suggests that the site is responding to a significant need, it also demonstrates that there is an increasing number of people who have become aware of haemochromatosis and are searching for information. Increased community and professional awareness is one of our objectives.

In addition to the raw data, we receive many complimentary comments on the site layout and content.

1300 019 028 Information Line

Five members of the committee volunteer to 'staff' the information line during office hours. At other times callers may leave a recorded message that will receive a response on the next business day. In 2015 -16 we received 698 calls. While two thirds of all callers come to us after finding the number on our website, others are referred by health professionals or through advertising and broadcast publicity.

No Australian should suffer harm from haemochromatosis.

The content of calls varies widely. People with the condition, their relatives and sometimes their general practitioners seek advice and information. Many calls lead to printed information being mailed out. Occasionally callers also choose to join HA but the provision of information is free and never dependent on membership.

Sometimes the information shared seems less important than the opportunity for the caller to talk through some of their experience of haemochromatosis.

This is a highly valued service with many callers expressing gratitude for the opportunity to discuss their condition or that of a relative. It is also a strong link between us and the people we serve, keeping us in touch. We talk with people who have been diagnosed after years of suffering. We hear people tell us they now understand why a parent died young with liver disease.

Social media

The HA Facebook page continues to prove a popular forum with members and supporters with over 3000 Likes. Twitter adds considerably to HA social media reach via @HaemAus. There are now 428 Followers. A considerable number of these are both Australian and international health and government organisations. These include a number of Primary Health Networks, Local Hospital Districts, HealthPathways Community gateway, and education providers including Medicine Today and GPCE. Whilst there are still relatively few Australian individuals following @HaemAus, current followers are increasingly engaging with the content posted.

It is interesting to contemplate how the increase in use of social media and the website relate to the slight reduction in use of the info line.

Video package

Our collection of haemochromatosis videos on YouTube and our website continues to be a popular source of information; in particular, the short animated explanation of the condition and the 10-minute, more comprehensive video. The following shows the number of times they have been viewed.

	All time	2015/2016Year
Animation	32,120	17,744
Haemochromatosis Explained	17,732	9,581
TV Commercial	1,036	371
Total	58,888	27,696

Haemochromatosis: your questions answered

This booklet was launched in 2012 and has proved to be very well accepted. It is distributed free-of-charge to individuals, organisations and clinics. It appears to be accepted as the principal patient information document for haemochromatosis in Australia. In 2015/16 we distributed approximately 3,000 copies. Since launch we have distributed 14,000 copies.

Overload exhibitions During the awareness week in 2015 there were wonderful Overload art exhibitions in Hobart, Deloraine and Wollongong. These events raise awareness by gaining significant publicity, as well as raising some money and being delightful in their own right.

Pamphlets in Medical Centres

A new initiative this year, which was enabled by a very generous donation, has been a contract with INFO_MED to put our pamphlets in medical centres for a trial period of two months.

In Victoria the HA brochure is displayed in 1,050 GP Medical Centres, where 4,945 GP's work full time, where there are 4,945,000 patient appointments every 2 months. In South Australia the HA brochure is displayed in 230 GP Medical Centres, where 1,136 GP's work full time, where there are 1,136,000 patient appointments every 2 months. In Western Australia the HA brochure is displayed in 260 GP Medical Centres, where 1,445 GP's work full time, where there are 1,445,000 patient appointments every 2 months.

It will be interesting to see how many calls these generate to our information line, as an indication of their effectiveness.

2. Professional awareness

While haemochromatosis continues to become better known and understood, there is still too much evidence of people whose symptoms have been missed. HA seeks to raise the level of suspicion of the condition amongst general practitioners and to assist them with relevant information.

On-line learning package

The excellent online learning package for GPs, prepared by committee member and GP Liaison Officer Dr Katie Goot, has been well accepted on the ACRRM (Australian College of Rural & Remote Medicine) system. There have been 493 enrolments, 286 completions and many very favourable comments. This is a huge contribution to professional development.

GP Resources

The "GP Resources" section of our website brings together in one place all the information that a GP might need to manage a person with haemochromatosis.

Primary Health Networks and GP organisations

Health Sector Engagement.

Karin Calford has continued to engage with the primary health sector where possible, and with a particular focus on HealthPathways. This year, Townsville, and the Illawarra released a Haemochromatosis HealthPathway providing local health professionals with quick simple access to both clinical information and patient resources. Two other regions have almost completed a Pathway, and approaches to other regions have initiated the commencement of three more Pathways, with two others about to commence development shortly. Other organisations have also responded positively to a request to give attention to haemochromatosis. Some state Health Consumer groups e.g. NSWHealthConsumers and Health Consumers Qld share HH-related posts via social media. Approaches have been made to a number of health-related organisations, including NPS; the Pharmacy Guild; Pharmaceutical of Society Australia; National Blood Authority; INFO-MED and Norman Swans' Tonic health media group and more.

Constructive relationships have developed and positive outcomes achieved as a result of this outreach. For example, The Pharmacy Guild has come on board with Awareness Week 2016, and NBA has listed HA as an External Resources provider at <https://www.blood.gov.au/implementing-pbm> .

INFO-MED delivered HA brochures to GP surgeries in 3 states. In addition to these tangible outcomes, a number of major health organisations are currently holding internal conversations that may result in further increasing public visibility of haemochromatosis.

Biennial conference

During this year much time effort and energy has gone into preparing for the second Biennial Australasian Haemochromatosis Conference which will be held in Brisbane in August 2016, at the opening of the Awareness Week. The conference, with two international speakers, will be for both professional and consumer audiences.

3. Research

HA continues to be included in the MI-Iron Investigator team, led by Professor Martin Delatycki at the Austin Hospital. This important research into the impact of moderately elevated levels of iron may be ready to present significant results within the next 12 months.

We continue to support Barbara de Graaff in her important 'Haemochromatosis in Australia: A Cost of Illness Study' which is based at the Health Economics Unit of the Menzies Research Institute, Hobart. Her results will be published at our biennial conference in Brisbane in August 2016.

We have also supported Jessica Pearce, 6th year medical student from James Cook University, Townsville, in her Honours Research project 'Factors Influencing Self-Management of Haemochromatosis'.

We have provided information and advice to a number other research projects through the year.

4. Community awareness

The community service ads have been played predominantly on Southern Cross regional TV stations. We do not receive reports on their frequency but they do influence the pattern of calls to the info line. They seem to have been played less frequently this year and probably need to be renewed.

Volunteer Advocates

For many years a number of members have taken the initiative to work in their local communities to raise awareness of haemochromatosis. Advocates have pursued their awareness raising tasks in various ways.

Judi MacDonald continues to do outstanding work in the North East Victoria area. Her links to the car racing community have achieved spectacular publicity.

Sheila Stevenson puts in a great effort in northern Tasmania with the help of her husband and fellow volunteer Bernie. She achieved three radio interviews, six talks to groups, three newspaper articles and one public meeting, as well as one Overload art exhibition.

Barbara Charles has continued to be very active in the Blue Mountains where she has held a number of meetings each year as well as chasing up local difficulties with access to venesection.

Sarah Weaver ran the ever increasing Overload exhibition in Hobart for the fourth occasion and achieved much publicity including very valuable TV exposure.

Sheryl Brannan was active in Townsville and with husband Tom took awareness raising overseas while, visiting France and amassed quite a collection of photos with haemochromatosis banners at scenic locations throughout France.

Tony Marshall ran the wonderful Wollongong version of OVERLOAD which attracted a lot of media and public attention including radio and print interviews and addressed a U3A group. These are just some of our Volunteer Advocates. Together they make a most important contribution to raising awareness.

Haemochromatosis Awareness Week

The purpose of the awareness week is to achieve a better rate of timely detection, diagnosis and management through improved awareness in the general community and in the health professions.

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.

This is the fourth year that we have promoted the Awareness Week. It seems to be gaining a momentum of its own. We were contacted by many health authorities and medical practices asking us for display materials and resources. While we still need to work hard to try to get attention from national media during the week, we found this year that we had more success, especially on radio. We had interviews or information segments on ABC radio in Adelaide, Melbourne, Hobart, Horsham, Eyre Peninsula and Mt Gambier, radio 2GB in Sydney, several community stations and an hour-long haemochromatosis segment on Dr Sally Cockburn's Health Matters show on Melbourne 3AW. A WIN TV news story with HA committee members Tony Moorhead and Linda Rule about therapeutic donations at the Red Cross Blood Service gained a lot of publicity and was picked up by WIN stations around the country. Newspaper articles were published around the country with a major feature in the Adelaide Advertiser a highlight. Social media and awareness information on websites by health authorities also proved very fruitful.

5. Health policy improvement

There are many things that can be done to improve the response to haemochromatosis but we will not get close to our vision that No Australian will suffer harm from haemochromatosis without improvement in the associated national health policy.

At the conclusion of the 2014 Australian Haemochromatosis and Iron Overload Conference we held a panel discussion with a most eminent group on the topic "To screen or not to screen?" The panel and the audience were all firmly and clearly of the view that we should have a national screening program to detect haemochromatosis before it causes a problem. A preliminary submission to the Medical Services Advisory Committee was unsuccessful. It is reasonable to hope that when the Mi-Iron research and the Cost of Illness study are complete there will be an increasingly strong basis for pressing a stronger case for much more preventive genetic testing.

6. Society administration and governance

In 2010 we changed our counting of membership to only include those who were financial or who had been financial within the previous 12 months. Total membership grew in the

next few years from 800 to almost 1500. It has always been the case that some people join for a year or two, gain the information and support that they need and then leave. Others join and remain loyal for years. However, the rate of new recruits has declined in the last two years and our total membership as at 30th June was 1193, a reduction of 51 from last year.

The principal service to our members, after the initial package of information is the quarterly newsletter. This is one of the many tasks undertaken by Tony Moorhead, in addition to his very substantial administrative load, and it is a significant and much appreciated contribution.

The financial reports are attached.

We resolved some time ago to not make fundraising a major focus of our activities, but it is notable that we have received no government funding or commercial sponsorship in the past year.

We continue to operate as an entirely voluntary body. Our committee of eight is scattered across four states. This year we had one face-to-face committee meeting at the time of our annual general meeting in Wollongong. All the rest of our business is conducted remotely by Skype, email and suchlike.

The efficiency of modern communications is such that we do not have the burden of maintaining an office or other physical infrastructure. This enables us to devote a very high proportion of our resources to direct service delivery.

We acknowledge the very generous contributions of our team of Medical Advisers.

Conclusion and looking ahead

This has been another busy and exciting year for Haemochromatosis Australia. While it is interesting to focus on the highlights it is important to acknowledge the tremendous value of the continuing, everyday tasks of supporting people with haemochromatosis and distributing appropriate information. Servicing the Info Line, knowing that each call is from somebody deeply affected in their individual way, is a substantial and very valuable task. Maintaining and distributing our information resources is also an essential, continuing activity. The newsletter is vital in holding us together as membership based organization. Developing links with other health organisations contributes to our cause.

After six years as president I shall be stepping down at the annual general meeting in August 2016. It has been an enormous privilege to be a member of the HA team. I consider that the generosity and enthusiasm of all team members has enabled us to achieve much for the haemochromatosis cause in Australia, but of course there is much still to be done.

I would like to express my gratitude for the friendship and dedication of my colleagues. I step down confident that HA is in very good hands.

Ben Marris
President