

‘TIME FOR CHANGE’ WORKSHOP – 12 DECEMBER 2009

A Workshop took place in Brisbane on Saturday the 12th of December to discuss the future direction of the Haemochromatosis Society of Australia (HSA). The Workshop followed the letter circulated in August by Margaret Rankin, founder and President, seeking expressions of interest to ensure the continuation of the Society.

The Workshop was well attended by volunteers from several states: Queensland, New South Wales, Victoria, South Australia and Tasmania.

The stated purpose of the Workshop was: to review the purpose of the Society; to assess its strengths, weaknesses, opportunities and threats (SWOT); to consider the options for the future, including ‘going national’; to propose an outline of a plan for the future; and to identify ways to prepare a business and operational plan for the transition phase.

The Workshop was held at Margaret’s home in Coopers Plains and commenced with an opening statement from our host. Workshop participants then briefly introduced themselves, describing their backgrounds and interest in the Society.

The Workshop firstly voted on the principal aims of the Society. In order of priority, they were listed as:

1. to provide information on Haemochromatosis to people with the disorder;
2. to educate general practitioners and other health professionals on the disorder;
3. to promote awareness of hereditary Haemochromatosis generally, including to young people;
4. to provide ongoing support to members; and
5. to provide research support.

The Workshop also found that the aims at the front of the HSA publication ‘A Practical Guide to Haemochromatosis’, constituted a suitable mission statement for the Society’s activities in general. These aims are:

- To improve awareness and knowledge of Haemochromatosis.
- To provide information to all interested persons, about the nature of this disorder.
- To assist in the early identification and treatment of those most at risk, to avoid the life threatening consequences of uncontrolled iron overload.
- To assist carriers, sufferers and other interested persons with understanding of the diagnosis and management of this most common genetic disorder.

The Treasurer, Brian Smith, then provided a brief summary of the Society’s financial position. The Society’s annual income of around \$30,000 is principally derived from membership fees and donations. A membership of 1,200 was cited, but only 850 members are currently financial. Expenses generally match income and the main expenses were identified as the printing of the newsletter, postage and printing of the HSA publication ‘A Practical Guide to Haemochromatosis’ (not an annual expense).

Consideration was then given to the Society’s strengths, weakness, opportunities and threats. Some of the items raised will be addressed in the short term and others will be included in longer planning initiatives.

The Society has the capacity to build on its many strengths. It was acknowledged that the ground work has already been laid - the HSA has a website, the 'A Practical Guide to Haemochromatosis' and venesection record publications, contacts with researchers and an active voluntary membership in most states. Margaret has agreed to provide continuing patronage and we are all motivated by the common bond of our passion to communicate information about Haemochromatosis. The move to build on the already established national structure was also viewed as positive for the future growth of the Society.

The Workshop identified a number of weaknesses that the Society must work to overcome. These are the limited number of volunteers working to advance the Society, a structure that does not support succession planning, the Society's low profile in the broader community, a lack of referrals from medical professionals and other organisations, a lack of funding and a lack of avenues for two-way communication with the membership.

There were many perceived opportunities for growth of the Society's activities and reach. These include fund raising activities (particularly accessing prevention dollars), encouragement of volunteer roles, advance planning to allow for a smoother succession of all roles, development of our internet presence (including social and new media), education of medical professionals, education in schools, development of strategic relationships (e.g. Red Cross, pathologists, 1300HELP), promotion of the public cost of untreated Haemochromatosis and establishment of a national Haemochromatosis day/week.

Threats to the Society's continuation were identified as a lack of succession planning, a lack of general awareness of Haemochromatosis, insufficient resources to meet growth in administrative tasks, organisational history (which may lead to complacency or an exhaustion of ideas) and a lack of feedback from the membership.

The Workshop quickly agreed that a national management structure with an indefinite number of branches in cities and regions across the country was the preferred option for the Society in the future. Some discussion followed of possible arrangements on the national and local levels. It was decided that research into alternative structures was necessary and appropriate legal advice would be obtained before a final decision was made.

The participants at the Workshop agreed to form a National Steering Group to guide the Society through this transition phase. The aim is to have an agreed structure in place before the next Annual General Meeting in August 2010.

Workgroups were established to advance the immediate tasks. These tasks included research into alternative structures for a national organisation, research into collaboration tools to facilitate further meetings of the National Steering Workgroup and a newsletter to communicate the outcomes of the Workshop to members.

The Workshop concluded with a discussion of current administrative tasks and any assistance Margaret may require to support the running of the Society through to the AGM.

The feedback from the Workshop participants was positive and everyone was excited about the Society's future. It was clear that the challenges inherent in this transition phase offer a wonderful opportunity to advance the overall aims of the Society.

The National Steering Group will meet again in mid-February to discuss the research on possible management structures and other identified tasks. The outcomes of this and ongoing meetings will be posted on the Society's website and further newsletters.

Members are welcome to discuss the outcomes of the Workshop with the participants and to contribute ideas for discussion. The contact details for the National Steering Group are:

National Steering Group – Contacts

Marg Rankin	QLD	07 33450581
Linda Rule	QLD (Sunshine Coast)	07 54411035
Tony Moorhead	QLD (Sunshine Coast)	07 54388267
Brian Smith	QLD	07 33976724
Marea Petty	QLD	07 38022181
James Stephenson	QLD	0411 627477
Bill McNeill	QLD	07 33682749
Val Bell	QLD	07 3796722
Ben Marris	TAS	03 62674787
Karin Calford	NSW	02 49597674
Traicee Evison-Griffith	VIC	03 55683163
Desma Wieringa	SA	08 82982026