



## Mission Statement

***"To improve the well-being  
of the Haemophilia community  
through mutual support,  
networking, advocacy and striving  
for optimal health care."***

The five main areas in which HFACT operates are:

Advocacy	<i>Awareness of Haemophilia issues through education and constructive representation</i>
Services	<i>Ready access to optimal health care and attention to issues that may arise</i>
Networking	<i>Ongoing interaction with related agencies</i>
Membership	<i>A strong and enthusiastic membership body</i>
Governance	<i>Open and effective management</i>

**HAEMOPHILIA FOUNDATION  
AUSTRALIAN CAPITAL TERRITORY  
INCORPORATED**

**Advocacy** – Key areas for 2012 to 2014:

Issue (In Priority Order)	What
1. Maintain a public profile for people with haemophilia in the ACT	<ul style="list-style-type: none"><li>- Represent people with haemophilia and related bleeding disorders at public events of relevance to the group</li><li>- Participate in relevant committees and advisory bodies on behalf of the members</li><li>- Advocate with Government to improve treatment and outcomes for people with haemophilia</li></ul>
2. Raise the awareness of haemophilia among health care professionals	<ul style="list-style-type: none"><li>- Identify ways to inform the medical community about haemophilia, treatment and complications</li><li>- Support and participate in education programmes provided at the hospital for medical staff to ensure multi-disciplinary outcomes</li></ul>
3. Raise the awareness of haemophilia in the community	<ul style="list-style-type: none"><li>- Identify avenues and opportunities to draw the attention of the public to haemophilia and the issues faced by people with the disorder.</li><li>- Participate in national awareness campaigns</li><li>- Develop a brochure that provides basic information about the foundation for people in the ACT</li><li>- Provide useful information to improve awareness of haemophilia in schools and sporting groups</li></ul>

## **Service Provision** – Key areas for 2012 to 2014:

<b>Issue (In Priority Order)</b>	<b>What</b>
1. Maintain and improve access to the latest and safest haemophilia treatment products	<ul style="list-style-type: none"> <li>- Maintain awareness of treatment products and technologies, scientific and medical advances in haemophilia care</li> <li>- Encourage good record keeping to ensure that the contract decision makers are aware of the effectiveness of products and/or issues with treatment</li> </ul>
2. Lobby for optimal service provision for persons with haemophilia	<ul style="list-style-type: none"> <li>- Ensure the ongoing operation and accreditation of a Haemophilia Treatment Centre in the ACT</li> <li>- Hold regular meetings with the management of the Haemophilia Treatment Centre to ensure that issues and concerns are handled</li> <li>- Lobby for adequate nursing services to manage haemophilia and all the associated issues</li> </ul>
3. The continuation and improvement of a counselling service to the members	<ul style="list-style-type: none"> <li>- Ensure that members have access to a comprehensive counselling and support service</li> <li>- Provide a suitable working environment for the counsellor to operate</li> <li>- Conduct regular reviews of the counsellor's duties and reporting mechanisms and identify ways that the service can be optimized.</li> <li>- Identify resources to assist the counsellor in his/her duties.</li> </ul>
4. Provide a quality support service to members	<ul style="list-style-type: none"> <li>- Develop a programme of activities that addresses the needs of the membership</li> <li>- Develop a set of resources to be available to the membership and prospective members</li> <li>- Identify ways of quantifying the services provided by HFACT in terms of cost effectiveness and outcomes</li> <li>- Research other avenues of funding (outside of government) in order to ensure the viability of the services provided.</li> </ul>
5. Ensure members have access to the full range of health services required to maintain quality of life	<ul style="list-style-type: none"> <li>- Identify the health services and health providers that need to cater for specialised haemophilia care.</li> <li>- Ensure ACT health providers are educated in optimal haemophilia treatment practices.</li> <li>- Provide a resource to individuals with haemophilia listing health carers in the ACT with specialised knowledge of the haemophilia condition and related medical issues such as HIV and Hepatitis C.</li> <li>- Establish a project aimed at addressing Hepatitis C issues for members</li> </ul>
6. Strive to reduce the negative experiences and treatment delays for individuals with haemophilia, and their parents, presenting to the Accident and Emergency Department at TCH.	<ul style="list-style-type: none"> <li>- Review the experience and documentation of incidents at A&amp;E and determine a strategy to address the problems</li> <li>- Establish a journal of incidents that have been either formally or informally reported to the counsellor or HFACT executive.</li> <li>- Develop guidelines for patients seeking treatment at A&amp;E to assist them in documenting their experiences</li> </ul>

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**Membership** – Key areas for 2012 to 2014:

<b>Issue (In Priority Order)</b>	<b>What</b>
1. Encourage an active and supportive membership	<ul style="list-style-type: none"><li>- Develop a programme of interesting activities that will entice members to participate</li><li>- Provide at least one major social event, and several other events throughout the year</li></ul>
2. Attract people to participate in the committee	<ul style="list-style-type: none"><li>- Keep the membership informed about the committee and its operations</li><li>- Personally approach members to participate on the committee</li></ul>
3. Maintain an awareness of the needs of members	<ul style="list-style-type: none"><li>- Keep in touch with all members through informal contacts by the counsellor and committee members, using all means such as email, telephone and face-to-face meetings</li><li>- Conduct occasional surveys or other analysis of needs</li></ul>
4. Keep members informed	<ul style="list-style-type: none"><li>- Produce four newsletters per year</li><li>- Provide an email option for newsletters and updates</li><li>- Maintain a current and informative web site</li></ul>
5. Attract new members	<ul style="list-style-type: none"><li>- Ensure that new patients presenting at the Haemophilia Treatment Centre are provided with information about the existence of the Foundation in the ACT</li><li>- Encourage non-financial members to become financial</li></ul>

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**Networking** – Key areas for 2012 to 2014:

Issue (In Priority Order)	What
1. Interaction with other Haemophilia Foundations in Australia	<ul style="list-style-type: none"><li>- Cooperate and contribute to the national Haemophilia Foundation through the HFA council and regular contact with the Executive director and/or President</li><li>- Maintain regular contact with other Haemophilia Foundations</li><li>- Encourage member participation in Family camps and similar activities conducted by other Haemophilia foundations</li></ul>
2. Interaction with similar groups in the ACT	<ul style="list-style-type: none"><li>- Maintain liaison with other non-government agencies involved in the support of medical conditions that are related to Haemophilia</li><li>- Participate in formal and informal network meetings of government and non-government agencies</li></ul>
3. Attendance at conferences	<ul style="list-style-type: none"><li>- Encourage and sponsor attendance by members at national and regional conferences on issues related to the membership</li><li>- Participate in the biennial National Haemophilia Conference</li><li>- Encourage involvement with the organisation of the WFH congress in Melbourne in 2014</li></ul>
4. International liaison	<ul style="list-style-type: none"><li>- Encourage and sponsor attendance by members to international conferences on Haemophilia and related diseases</li><li>- Give consideration to participation in the WFH twinning programme</li></ul>

## **Governance** - Key areas for 2012 to 2014:

<b>Issue (In Priority Order)</b>	<b>What</b>
1. Ensure adequate funding to provide services and administrative requirements	<ul style="list-style-type: none"> <li>- Maintain our strategic directions to define the role of HFACT in the provision of services for the haemophilia community to be used in negotiation with government.</li> <li>- Produce annual forecasts of income and expenditure.</li> <li>- Negotiate agreements with the ACT government for the provision of a haemophilia counselling service</li> <li>- Develop business continuity plans and risk analysis to ensure HFACT can remain viable without grant funding, if required.</li> <li>- Develop a fundraising programme to supplement government funding for special projects.</li> </ul>
2. Provide good financial and general management for the Foundation	<ul style="list-style-type: none"> <li>- Identify clear procedures for end of financial year, periodic reporting and other financial processes.</li> <li>- Provide transparency of all financial transactions to members of the committee through appropriate reporting.</li> <li>- Provide training to members of the committee on interpretation of financial statements and on committee member's legal responsibilities.</li> <li>- Provide committee members with details of minutes and financial statements in a timely manner to ensure individuals can properly review and question.</li> </ul>
3. Define procedures for various aspects of committee roles	<ul style="list-style-type: none"> <li>- Review job specifications for all committee roles.</li> <li>- Identify all tasks and responsibilities for the particular committee roles.</li> <li>- Prepare guidelines for the filling of positions on the committee.</li> <li>- Provide appropriate training to individuals who take on a committee role.</li> <li>- Train committee members on contract management and payroll procedures.</li> </ul>
4. Manage the employment of a counsellor and the ACT government service contract with diligence and integrity	<ul style="list-style-type: none"> <li>- Provide financial and activity reports in accordance with the service contract with the ACT government</li> <li>- Carry out six-monthly performance reviews with the counsellor, based on key expected results.</li> <li>- Provide opportunities for professional development for the counsellor.</li> <li>- Maintain a professional Employer/Employee relationship providing regular payroll and entitlement information</li> </ul>
5. Maintain an enthusiastic committee	<ul style="list-style-type: none"> <li>- Establish regular social events for the committee</li> <li>- Ensure committee members have benefits of attending professional development and conferences.</li> <li>- Nominate recognised awards to outstanding committee members who have made a generous contribution to the haemophilia community in the ACT</li> </ul>
6. Increase the number of committee members (and those who attend committee meetings)	<ul style="list-style-type: none"> <li>- Appoint understudies for committee positions to equip them to take on the position</li> <li>- Promote the benefits of being on the committee.</li> <li>- Promote the organisation and the benefits it provides its members to the wider ACT community.</li> <li>- Approach other volunteer organisations for resources</li> </ul>