



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
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Advocacy – Key areas for 2006 to 2008:

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

Service Provision – Key areas for 2006 to 2008:

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

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Membership – Key areas for 2006 to 2008:

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

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Networking – Key areas for 2006 to 2008:

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

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Governance - Key areas for 2006 to 2008:

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