

### 5e: Haemophilia Society Equal Opportunities Policy

The Haemophilia Society is committed to the principle of equal opportunities for all people, regardless of age, class, race, colour, ethnic origin, nationality, gender, disability or health status, religious belief, sexuality, parental, carer or marital status. Under this principle, we are working to promote equal opportunities and eliminate any possible discrimination in all our activities, including our service delivery, our employment and personnel practices and within the management and governance of the organisation. We are committed to ongoing review of our activities to ensure progress towards our equal opportunities goals.

Our commitment to equal opportunities includes the following practical measures as resources permit:

#### Service Delivery

- We aim to provide our services with regard to the identified needs of the whole community of people with haemophilia and related bleeding disorders and will undertake regular needs assessment to ensure this is put into practice.
- We will ensure our service delivery is guided by the needs of users, and is designed to overcome barriers to access which may potentially exclude certain groups.
- We will maintain monitoring and evaluation systems to provide information on uptake and use of our services, with periodic review of the profile of our service users.
- Where our monitoring evidence indicates the need, we will take positive steps to reach groups who may not be fully accessing and utilising our services.
- Our equal opportunities policies will be included in the job description, and/or role of all staff, and volunteers to ensure continuing commitment to implementation of the principle.

#### Employment and personnel practices

- We will work to ensure the Society is an equal opportunities employer, and to demonstrate actively that we welcome diversity among our staff and volunteers and follow current good equal opportunities practice in recruitment and employment.
- Where resources permit, we will provide basic equal opportunities training for staff and Trustees, and additional role specific training when necessary.
- We will regularly review our selection criteria and recruitment procedures to ensure individuals are treated equally on the basis of their skills and abilities.
- All recruitment advertising will include the phrase **The Haemophilia Society is committed to Equal Opportunities**, and information to applicants will include a copy of this policy.

#### Management and governance

- We will work to reflect equal opportunities in our management and governance systems, including regular review by the Board of Trustees of the impact of our equal opportunities policies.
- Within our Board and committee structures we will seek to achieve diversity and balance of membership, to avoid any possible discrimination or exclusion, and to work to increase minority groups participation wherever possible.

Karin Pappenheim September 1998

### 5f: Working with Commercial Organisations

1. The mission of the Haemophilia Society, as the UK patient group, is to secure the best possible treatment, care and support for all people with bleeding disorders and their families. To achieve this mission we welcome partnerships with and support from other organisations, including commercial companies.
2. The purpose of this policy is to set out a clear framework for the Society's relationships with commercial companies, particularly those which manufacture and market treatment products relevant to our membership group. We acknowledge the importance of the financial support provided to the Society from commercial companies, which is a significant part of our funding base as a charity. At the same time the Society must protect its independence, and we need to safeguard that independence carefully in our relationship with funders.
3. This policy has therefore been produced to explain the Society's stance in relation to funding from pharmaceutical and other companies with an interest in the field of haemophilia care. We want to maintain positive, co-operative and mutually beneficial relationships with pharmaceutical and other companies. In order to achieve this we believe both parties should be clear about what they can and cannot expect from the relationship and what the limits and boundaries are.
4. We recognise that many companies wish to contribute to charities through a sense of corporate responsibility, and in this field through a desire to give something back to the haemophilia community. This may lead to donations not only of money but also of help in kind. Such help in kind is welcome, as are open ended donations which the Society may use as necessary to fund any aspect of our work. This type of 'unrestricted' funding is of most use to the charity.
5. Equally, we recognise the principle of mutual benefit. We appreciate that where funding is provided from a marketing or advertising budget there may be a need to be more specific in linking it to a particular activity. Our general approach is to negotiate on a project by project basis with each company so that the needs of both parties can be considered.

#### Principles

1. **The Haemophilia Society as a national charity operating in a small, very specialised area of healthcare must be very careful to maintain its independent stance. With regard to the field of haemophilia care we stand for patient choice, and support developments which widen that choice and improve the safety and efficacy of treatment methods.**
2. **When working with commercial organisations, the Society must take care that our unbiased, independent advice and information to people with haemophilia, their carers and health professionals and our campaigning stance is not influenced in any way.**
3. **Thus, the acceptance of financial support from a company does not confer any form of editorial control or influence over the policies of the Society. Those policies are determined by the membership and Trustees of the Society and are based on the identified needs of people with haemophilia.**
4. **As a general principle we will not endorse any brand of treatment product, and will not be associated with any advertising or promotional activity linked to a specific product. This means that whilst happy to give credit as sponsors to companies, we normally avoid mention of product names. Wherever possible in our literature discussing treatment options we will refer to generic types (i.e. recombinants, plasma derived) rather than brands.**
5. **In order to safeguard our independent standing, wherever possible, we prefer to have multi-sponsors for our work. This is particularly the case in relation to publications, such as our booklets and Bulletin, where sponsorship from one company alone might give the impression of bias. Hence, in general we will seek more than one sponsor for each of our publications, and for**

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### events for people with haemophilia.

6. The Society normally cannot take part in advertising or promotional efforts by individual companies. Hence, in our Bulletin we will not carry advertisements from companies, including flyers, and at our events we would not accept corporate exhibition or display boards and materials.
7. Increasingly we understand companies want to receive publicity for funding or other support provided to charities. Different companies have different policies and approaches to this. The Society will agree this on a project by project basis. The extent to which the Society itself is willing for our name to be used in associated publicity will also vary. We must safeguard against associated publicity being seen as a form of endorsement. Any publicity or promotion should be agreed between the company and the Society's chief executive.
8. The Society seeks to maintain relationships on equal terms with all companies with an interest in this area of healthcare; and cannot be involved in attempts to give one company a competitive edge over others.
9. As a charity, maintaining positive relationships with all our funders is crucial to our survival. We must also abide by charity law and the requirements of the Charity Commission, and it is the Society's aim as an organisation to follow best practice in the charity sector. This involves openness and transparency in our activities, one aspect of which is being open to our members, other funders and the general public about the charity's sources of funding and fundraising approaches. Our funders are listed in the annual report for this purpose.

### Specific rules

1. At no time can the charity's logo and name be used without the express permission of the Chief Executive.
2. Press releases cannot be issued which refer to the Society without the prior approval of the Chief Executive; suggested quotes to be used in releases must be cleared via the Society's press officer.
3. A company's support will be acknowledged in an appropriate way determined in advance following discussion with the company.
4. In general we will seek an exchange of letters of agreement where funding is to be provided from a company so that it is clear to both parties what funding will be used for.
5. We reserve the right to withdraw from any funding arrangement if it appears to threaten the good name or reputation of the charity.
6. The Society will not release the contact details of individual members without their express permission.
7. The Society will not give access to its membership mailing list without the approval of the Chief Executive.
8. The Society may, if appropriate offer endorsement of certain research, such as surveys. However, each case will be judged by the Chief Executive on its individual merits.

**Karin Pappenheim**  
Chief Executive  
17 May1999