



THE
HAEMOPHILIA
SOCIETY

INDUCTION PACK FOR NEW TRUSTEES

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Introduction

Welcome to the Board of trustees of The Haemophilia Society. Your first point of contact at the Society on anything regarding your trusteeship, board meetings, travel or accommodation arrangements are the Chief Executive, Liz Carroll and her PA Fiona Donoghue.

Overview

The Board of trustees is the body that is legally and financially responsible for the organisation as a whole. The board as a whole is responsible, therefore each member is therefore equally liable.

Trustees

We have seven elected trustees, one Honorary Chair and up to four co-opted trustees. Elected trustees are elected by the members of the charity and announced at the Annual General Meeting (AGM). The rules of the election are set out in our constitution (known as the Memorandum and Articles of Association (M&A)). Co-opted trustees and the Honorary Chair are appointed to the board under the same terms as elected trustees; they are appointed to ensure a diverse, skilled board.

Each trustee is elected or appointed for a three year term, they can stand for two terms, then must have a year break. They may then stand for an additional three years, when they must stand down and can't be re-elected. Our Board of trustees currently meet about every two months on weekdays in London.

As The Haemophilia Society is a charitable company you are a both charity trustee and a company director. Your liability as a Company Director is limited to £1 as long as you act in accordance with the terms here and in the trustee agreement.

What does the Board of trustees do?

As a member of the board of trustees you are bringing your skills, knowledge and experience to:

- make sure that the organisation meets the needs of the people it was set up to support
- make sure that the organisation is open equally to everyone and that you do not discriminate against anyone
- make sure that the organisation is accountable to its members and to the wider community
- make decisions about the organisation's objectives, policies and procedures
- work in partnership with paid and unpaid staff so that they can get on with their jobs
- keep the organisation within the law and provide a safe and healthy place for people to be in
- act in a fair and responsible way to any paid and unpaid staff
- making sure that money is spent properly and reassure any funders that decisions are being made by a number of people
- make sure that the organisation has the resources - people, equipment, premises, insurances and money - to get on with its work
- monitor how well the organisation is doing its job
- take appropriate action when things are not going well
- represent the organisation at other meetings, forums etc.
- positively promote the organisation and its work.

Charity trustees have some additional legal responsibilities set out in Charity Law and Company Law and other relevant laws such as safeguarding, data protection, health and safety etc.

How does the board work?

The board meets about every two months, generally in an afternoon in London. Meetings always have minutes, which are approved by the Board at the subsequent meeting.

Sub-committees

We have one permanent sub-committee – Resources, and one occasional committee – Nominations. We also have a public inquiry subcommittee. These committees make sure that certain areas of work are carried out and activity considered in greater depth than the whole board is able to do. Resources look at finance, policies, procedures and human resources. Nominations meet to consider major appointments such as the Chair and Chief executive. The Public inquiry subcommittee are focussing on our work related to the inquiry for its duration.

Sub-committees aim to reduce the pressure on the board making it easier for trustees to contribute as the work is done in small groups involving staff. Sub-committees always report back to the main board to approve any recommendations.

What are my personal responsibilities?

As a trustee you should always:

- attend meetings regularly and arrive on time, you are expected to attend 75% of meetings per year. We will do all we can to accommodate any special needs you have
- give apologies if you can't attend and pass on any relevant information to the Board
- work as part of a team and take an active part in meetings
- keep to the point in discussions
- support each other, listen to others and try not to interrupt
- be prepared to share responsibilities and information
- ask if you don't understand something or need more information
- carry out what you have agreed to do
- make sure that decisions are made in a democratic way and abide by the decisions made
- remember, if you are representing the organisation at a meeting or event, that you are speaking on behalf of the board not yourself
- be non-discriminatory and promote equal opportunities

The Board of Trustees operates on the basis of collective responsibility. Collective responsibility means that, once a decision has been made, all trustees are required to abide by it and to defend it as necessary, even after their term of office has ended.

I should not...

- be disruptive or aggressive
- use bad or offensive language
- talk too much
- interrupt or shout
- keep information to yourself
- try to dominate the meeting or other board members
- make others feel inadequate, stupid or wrong for having a different opinion
- waste people's time

- develop conflicts of interest
- undermine staff and fellow trustees
- come unprepared to meetings
- use the organisation to satisfy personal needs.
- Disclose confidential discussions or personal information

A resolution was passed by the board of trustees in March 2018 that 'No person who is a primary employee of a pharmaceutical company may become or remain a Trustee because the existence of potential or actual conflicts of interest could be damaging to the Charity'

What about rights?

As a trustee you have the right to:

- be properly inducted to the organisation when you join
- to meet the relevant people and get the right information including annual reports, copies of the governing document, accounts and minutes of previous meetings
- be provided with the help you need to take a full part in the meeting such as travel and accessible venue
- receive training in the responsibilities of a board member
- receive the correct and up to date information in good time
- be consulted and have a full say in decision making. Everyone should be encouraged to have their say, so if you think decisions are being made by one or two people or the staff are always deciding what happens, say so
- take credit for the work you and the organisation have done
- enjoy yourself!

Papers for meetings will be sent out by email a week before the meeting, unless you require a paper copy. If you have any comments or would like to add anything to the agenda please contact the chair of the meeting or CEO before the meeting.

Mail addressed to Trustees (unless marked Personal or Private and Confidential) will be opened in the office and forwarded on.

Reasonable travel and other expenses are paid to trustees when receipts are provided and an expenses form completed. As a charity we aim to keep travel costs as low as possible and offer to book your travel for you to ensure the best possible fare. Alcohol is not funded by the Society. If in doubt, please contact the Liz or Fiona.

1. Procedural rules for election of the trustee Board, and powers and responsibilities of members of the Board

1. Election of the Trustee Board

- At least six weeks ahead of the AGM the Chief Executive will advertise the election procedures in writing to all members and via social media.
- Members of the Board will be elected by a ballot. The results will be announced at the AGM

2. Powers of the Trustee Board

- The overall monitoring of the management of the Society.
- The appointment, and management of the Chief Executive Officer (day to day management is delegated to the Chair).
- Making of such regulations and rules that they may deem necessary or expedient or convenient for the proper conduct and management of the Society.
- Establishment an approval of policies and plans for the running of the Society.
- Delegation of the day to day management of the Society and all other such relevant duties to the Chief Executive Officer, who shall report regularly to the Board.
- Establishment of all necessary Task Group and/or Sub Committees to facilitate the proper management of the Society with the guidance of the Chief Executive Officer.

2. Powers and responsibilities of the Chair

- The Chair may exercise their casting vote wherever necessary at any meeting of the Trustee Board.
- All members of the trustees Board, including the Chair and the Treasurer, have equal responsibility for protecting the charity's assets. All are accountable for the solvency and continuing effectiveness of the charity and the preservation of its assets and they must all exercise control over the charity's financial affairs. The Chair and Treasurer cannot commit The Society to any costs without the approval of a majority of the Trustee Board.
- The Chair and Treasurer cannot institute major changes of policy or administration without the approval of the Trustees Board.
- The Treasurer shall ensure that proper financial control is established and that all Trustees are provided with proper management accounts and other relevant financial information.

3. Legal obligations and responsibilities

- Each and every trustee is jointly and separately responsible in law for the general management and control of The Society.
- Each Trustee is bound to contribute personally to the assets of the Society, if necessary, in the event of it being wound up during his/her term of office or within one year of retiring from office. Liability is limited to £1.
- Trustees cannot receive remuneration from The Society, but will be paid reasonable travelling, hotel and other expenses properly incurred by them in their attendance at meetings.
- Each trustee is expected to attend a minimum of 75% of meetings a year of the Board or Sub Committee at any location specified in the UK by the Board of trustees, except in the case of incapacity or illness.
- For the avoidance of doubt, each Trustee can be held liable by any member of The Society for any proven acts of negligence committed either by themselves or by any other trustee in the management of The Society.

4. Code of conduct/practice

The Duties and responsibilities of the trustees of The Haemophilia Society

We are the only UK-wide charity for all those affected by a genetic bleeding disorder; a community of individuals and families, healthcare professionals and supporters.

For almost 70 years we have campaigned for better treatment, been a source of information and support, and raised the awareness of bleeding disorders.

We want to ensure that everyone affected by a bleeding disorder:

- Lives the best life that they can
- Never feels alone or isolated
- Feels empowered and confident

We do this by:

- Raising awareness about bleeding disorders
- Providing support at all life stages
- Influencing and advocating on policy and access to treatment

This requires trustees and those serving on the trustee board to be committed to serving the needs of everyone with an inherited bleeding disorder, regardless of personal or family interest. Equally, this demands special skills from those serving on the trustee board.

We recognise that trustees come from a wide variety of backgrounds and may have been elected by members of The Society because of relations with particular groups, or other interests, however their role on the Board is to ensure all areas of our community are considered and represented in our activity and funds are appropriately managed.

This Code of Practice aims to outline the role and responsibilities for trustees and potential Trustees.

Section 1: Requirements for new and prospective trustees

1. It is expected that a new trustee should be aware of and supportive of our policies, mission, values and strategic objectives.
2. The roles of trustees are defined in the role description. It is expected that prior to appointment a new prospective trustee will confirm in writing that these duties and responsibilities are clearly understood and no conflicts of interest exist.
3. The trustees direct the strategy of The Society through discussion and agreement at formal meetings. A new trustee must agree to participate to the full in the Trustee discussions and accept the majority decision. As a trustee you accept the legal responsibility and duty to act in the interests of the Society as a whole.
4. It is expected a new trustee understands the time commitment and how their skills or experience will contribute to the Society.
5. It is understood that a new trustee either has or within reasonable time will have:
 - a sound knowledge of The Society, its strategy, range of activity and purpose
 - an awareness and general understanding of the social, political and economic environment in which we work
 - an understanding of The Society's constitution
 - an understanding of The Society's financial resources/budgets and investments
 - an acquaintance with the staff responsible for The Society's operational management
 - an understanding of the way in which The Society is run on a "day to day" basis, an awareness and detailed understanding of the relationship between the Society's CEO, staff and the trustee body.
 - An understanding of the legal responsibilities of trustees and of the principles of good governance

- We provide a trustee briefing pack and governance training for all trustees, and in turn expects that the trustee accepts the need from time to time to undergo training
6. All new trustees will be asked to sign a trustee undertaking.

Section 2: Consensus decision making and collective responsibility

1. The primary aim of all trustees is to make an objective and constructive contribution towards the effective direction of The Society's affairs. This requires a commitment from the board to resolve conflicts of opinion, personality or policy.
2. The Board of trustees operates on collective responsibility and every effort will be made to ensure that every trustee has a chance to have their say, in an appropriate forum or manner, before a decision is taken. Collective responsibility means that, once a decision has been made, all trustees are required to abide by it and to defend it as necessary, even after their term of office has ended.

The principal of collective responsibility applies after a decision has been reached; it does not mean that there must be unanimity beforehand. Trustees can express their views frankly in internal discussion of an issue, but their membership of the trustee Board requires them to maintain a united front once decisions have been reached; to ensure that the privacy of opinions expressed in internal discussions is maintained; and to ensure that the internal processes through which a decision has been made are not disclosed.

The reason for the unanimity of communication once decisions are reached relates to the role of the Board of trustees as the leadership of The Society. That is, in order to operate effectively, The Society needs a clear lead to be given by the Board. Any other course of action fosters division and impedes the implementation of Board decisions and damages our external credibility.

Should a trustee be elected on a particular 'platform' or issue, they should address this issue by raising it within the Board at the earliest opportunity, and after debate, discussion and decision, the principle of collective responsibility as described will apply.

Section 3: Code of Conduct

In general, trustees should behave in such a way as to uphold the principles set below:

1. **Selflessness**
Trustees of The Society have a general duty to act in the best interest of The Society as a whole. They should not do so in order to gain financial or other material benefits for themselves, their family, their friends or any organisation they represent.
2. **Integrity**
Society trustees:
 - Should not place themselves under any financial or other obligation to outside individuals or organisations that might seek to influence them in their performance of their role
 - As well as avoiding actual impropriety, should avoid any appearance of improper behaviour
 - Should avoid accepting gifts and hospitality that might reasonably be thought to influence their judgement

3. Objectivity

In carrying out their role, including making appointments (including trustee appointments), awarding contracts, recommending individuals for rewards and benefits or transacting other business, Society trustees should ensure that decisions are made solely on merit.

4. Accountability

Society trustees:

- Have a duty to comply with the law on all occasions in accordance with the trust placed in them and in such a way as to preserve public confidence in the Society
- Are accountable for their decisions and actions to the public funders and service users. They must submit themselves to whatever scrutiny is appropriate to their role.

5. Openness

Society trustees:

- Must ensure that confidential material, is handled in accordance with the data protection act and with sensitivity;
- Should be as open as possible about their decisions and action that they take. They should give reason for their decisions and restrict information only when the wider interest clearly demands

6. Honesty

Society trustees:

- Have a duty to declare any interests relating to their trustee role and to take steps to resolve any conflicts that may arise. Where private interests of a trustee conflicts with their trustee duties, he/she must resolve this conflict in favour of the trustee role;
- Must make relevant declarations of interest in the different circumstances and roles they play both within and outside the Society.

7. Leadership

Society trustees:

- Should promote and support the charity, leading by example;
- Must respect the role of the chief executive. There will be circumstances under which trustees will be working directly with the Society's staff. Trustees and should respect the line management structure of the CEO and Chair.

8. Conflict of Interest

- Any trustee who has a financial interest in a matter under discussion should declare the nature of his/her interest and withdraw from the room, unless he/she has a dispensation to speak.
- If a trustee has any interest in the matter under discussion which creates a real danger of bias, that is, the interest affects him/her or a member of his/her household, more than the generality affected by the decision; he/she should declare the nature of the interest and withdraw from the room, unless he/she has a dispensation to speak.
- If a trustee has any other interest which does not create a real danger of bias, but which might reasonably cause others to think it could influence their decision, he/she should declare the nature of the interest, but may remain in the room, participate in the discussion and vote if he/she wishes.
- If in any doubt about the application of these rules, he/she should consult with the Chair,
- Trustees have a duty to declare any conflict of interest

- If any member of the Board believes there is a conflict of interest for any trustee that may contravene any charity law, the Board should consult the Charity Commission.

9. Mutual respect

All trustees will be expected to treat each other, and all members of staff with mutual respect and in a professional manner. This would include that trustees should not make or infer remarks of a personal nature about members of the trustee Board, staff or members of The Society and confine all comments, remarks and correspondence, to issues and policies under discussion. In addition, trustees will be expected at all times to respect the social diversity of members of the trustee Board and members of staff or members of The Society, including ethnicity, gender, sexual orientation, education, health and disability status.

10. External Communications

Trustees should not make public comments about or on behalf of the Society unless authorised to do so. Any public comments made about or on behalf of The Society, whether made as an individual or as a trustee, will be considered and will be in line with the principles outlined in Section 2 “Consensus Decision Making and Collective Responsibility” of this Code of Practice. This includes comments made if approached by the press/media or in the context of representing The Society on outside bodies or attending meetings on behalf of The Society.

Section 4: legal responsibilities

Trustees must act reasonably and prudently in all matters relating to the charity and exercise the same degree of care in dealing with the administration of the charity as a prudent person of business would exercise in carrying out their own or their business affairs.

Specific Obligations

Trustees must not let their personal interests affect their conduct as trustees, must not benefit from The Society, must comply with the constitution, protect The Society’s property, supply information required by the Charity Commission and apply the property of the charity for the purposes set out in the governing documents.

To Whom the Duties are Owed

Trustees duties are owed principally to the Crown and are enforceable by the Charity Commission.

Delegation

The general rule is that trustees must act in person and decisions concerning the charity must be taken by the trustees acting together.

Trustees may delegate work to staff and/or seek the assistance of professional advisers on technical matters and employ staff to implement their decisions.

Trustees have the general duty of protecting all the charity’s property. They are accountable for the solvency and continuing effectiveness of the charity and the preservation of any

endowments.¹ So they must exercise overall control over its financial affairs. They should ensure that the way in which the charity is administered is not open to abuse by unscrupulous associates or employees and that their systems of control are rigorous and constantly maintained.

Section 5: Sanctions for not observing the code

1. Reporting

Alleged breaches of the Code should be reported to the Chair (or the Vice-Chair if it is the Chair who has not complied with the Code), who will investigate the complaint or issue. If needed, the Chair will appoint a panel who will investigate the complaint.

1. The Panel

The panel should follow normal complaint procedures. It should take reasonable steps to establish the facts and ensure that the trustee against whom the allegation has been made is given a fair opportunity to put their case in writing or in person (whichever they prefer).

The trustee will also be entitled to be accompanied by a colleague or friend to any interview or panel that is convened. Legal representation will not be accepted in this first instance.

The panel should notify its conclusions and any recommendations for action to the whole Board. If this is the course of action deemed appropriate, the formal removal of a trustee will follow the process outlined in paragraph 67 of the Memorandum and Articles of Association – Disqualification and Removal of Members of the Trustee Board.

Further information on charity regulation and law is available from the Charity Commission. The following information may be helpful to read.

Charity trustee: what's involved (CC3a) <https://www.gov.uk/charity-trustee-whats-involved>

The essential trustee: what you need to know, what you need to do (CC3) <https://www.gov.uk/government/publications/the-essential-trustee-what-you-need-to-know-cc3/the-essential-trustee-what-you-need-to-know-what-you-need-to-do>

Conflicts of interest: a guide for charity trustees (CC29) <https://www.gov.uk/government/publications/conflicts-of-interest-a-guide-for-charity-trustees-cc29>

5. Roles and responsibilities

Role

To lead The Society towards realising its mission.

To ensure that the organisation is effectively managed.

To ensure that The Society complies with its duties under Charity and Company Law.

Responsibilities

Each and every Trustee is jointly and separately responsible in law for the general management and control of the Society.

Planning

To approve the charities mission statement and Strategy and review the staff's performance in achieving it.

To assess the changing environment and develop and improve the strategic plan with the Chief Executive Officer.

To approve and review the annual budget and operational plans.

To approve and review major changes to any of the above.

Organisation

To recruit, monitor, appraise, advise, support and, if necessary, replace the Chief Executive of the organisation and to regularly discuss with the Chief Executive matters that are of concern to him/her or to the Board.

To ensure that organisational strength and staffing is equal to the requirement of the long term plan and within the financial resources available.

To approve an appropriate salary, terms and conditions of the Chief Executive and staff salaries.

To approve the Chief Executive's work plans and review his/her performance.

To evaluate the performance of the Board and take steps (eg relating to its composition, organisation and responsibilities) to improve its performance.

Operations

To attend Board meetings and read Board papers in advance of meetings.

To participate in appropriate committees and working parties as necessary.

To act as a collegiate body with collective responsibility.

To approve The Society's plans and major changes in activities and services.

To evaluate the results achieved by The Society in relation to its mission, the operational plans and strategic plan.

To ensure that the financial structure is adequate for its current needs and its long range strategy.

To provide candid and constructive criticism, advice, comments and praise.

To promote the good name and reputation of The Society.

Audit

To ensure that the Board is adequately and currently informed of the organisation's activities and their effectiveness.

To ensure that published reports adequately reflect the nature of the services and financial condition of The Society.

To ensure that appropriate policies are established to define and identify conflicts of interest throughout the charity and that these are administered and enforced.

To appoint independent auditors subject to approval by members and approve the audited accounts.

To review compliance with relevant laws affecting the organisation.

6. Structure and Terms of Reference of Sub-Committees

The Sub-Committees are, as their name implies, accountable to the main Board. *Their primary focus is on policy and strategy rather than operational matters.* This is an essential point if confusion in lines of accountability and responsibility is to be avoided.

The role of the Sub-Committee is:

- To review the implementation of existing policies on an ad hoc or continuing basis as appropriate
- To consider policy change or the formulation of new policy within their specific specialist area as necessary
- To understand and provide leadership on issues relevant to the sub –committee, looking at the subject in detail
- To report to the main Board on the above, making recommendations where changes to existing practice is needed.
- Membership of each Sub-Committee will be decided at the first Board meeting following the AGM.

Membership of Sub-Committees

- Each Sub-Committee will be made of up four members, at least two of whom will be trustees.
- The Chief Executive will determine which staff will attend each Sub-Committee. This will include allocating a staff member to service each Committee. The Chief Executive will be free to attend any of the Sub-Committees, but will not be required to be a permanent member of all of them.
- Each Sub-Committee will be able to co-opt one or two additional non-trustee members with special expertise or experience if need be.

Resources

Remit: Finance, fundraising, investment and reserves policy; personnel and staffing issues with financial implications, such as salary and pay policy.

This sub-committee should function primarily as a finance committee, covering personnel issues when they have financial implications, and providing a source of financial expertise to advise the Chief Executive and main Board. It will be chaired by the Treasurer. It will have the key role in monitoring income and expenditure, forecasting and predicting financial risk, and in financial planning. This will include approving financial and fundraising strategies developed by the staff, and policies on areas such as investment, reserves. The role will include keeping a watching brief on latest issues in charity finance and law, to ensure that the Society complies with best practice and that trustees fulfil their financial responsibilities under charity and company law.

For this committee it will be essential to have among the member's individuals with financial expertise, and experience of business planning.

Nominations

Remit: recruitment of key positions such as the Chief Executive and Chair

This sub-committee will only meet as necessary and will cover the planning and process for recruiting the Chief executive and Chair positions. This will include approving any agencies or professional help to manage the day to day recruitment process, and leading the interview process.

7. Policies

Comments and Complaints Policy

The Haemophilia Society aims to provide a quality service and this policy is to ensure that there is a uniform approach to complaints.

1. What is a complaint?

A complaint is 'any expression of dissatisfaction that needs a response'. A complaint may be about service delivery, staff or the Society's policies.

2. What is a comment

Someone may make a comment that highlight a part of The Society's service that could be improved or a successful aspect of the service. Either way, it is important to record these comments.

3. Who may make a comment or complaint

- Members of The Society and their families
- Non-members of The Society affected by bleeding disorders
- Professionals
- Volunteers
- Local group representatives

4. Verbal comments and complaints.

4.1 Verbal comments

People may speak to staff members on the telephone or at an event to give feedback about The Society's service. Staff may record these comments anonymously or discuss feedback received with colleagues and managers in order to plan and deliver appropriate services.

4.2 Verbal complaints

People may speak to staff members on the telephone or at events and complain about The Society's service. The member of staff should acknowledge the complaint and ask if they would like it to be investigated. If the answer is yes, they should be advised to put the complaint in writing.

4.3 Verbal comments or complaints about individual staff members

Anyone making a comment or complaint about individual staff members should always be advised to put it in writing to the chief executive.

4.4 Verbal comments or complaints about the chief executive or individual trustees

Anyone making a comment or complaint about the chief executive or individual trustees should always be advised to put it in writing to the chair.

5. Written comments and complaints

Written comments and complaints are any correspondence received in writing by letter or email.

5.1 Written comments

People may write or email and give feedback about The Society's services. Written comments do not normally require any acknowledgement, however individual staff members may wish to thank people for their comments, whether positive or negative.

5.2 Written complaints

5.2.1 Stage One

People may write or email to complain about The Society's services, policy or staff. On receipt of a written complaint by email or letter, staff members, trustees and volunteers must immediately pass or forward the correspondence to the Chief Executive.

5.2.2 Stage Two

The Chief Executive or personal assistant will ensure that the complainant receives a written acknowledgement of their complaint within five working days.

5.2.3 Stage Three

The Chief Executive will carry out an investigation of the complaint. This may involve speaking with relevant staff members, seeking further information from the complainant or consulting external advisers. The investigation should not normally take more than two weeks.

5.2.4 Stage Four

The Chief Executive will write to the complainant within 28 days of his/her initial correspondence with the results of the investigation, an apology if appropriate and the details of any action to be taken as a result of the complaint.

5.2.5 Stage Five

If the complainant is not satisfied with the response he/she may write to the Chair of the Board of trustees who may take the matter up with the Chief Executive, discuss it with members of the Board or consult external advisers the same timescale as above will apply to written complaints to the chair.

5.3 Written comments or complaints about individual members of staff or volunteers

Any written comments or complaints about members of staff or volunteers should be passed immediately to the Chief Executive and treated as private and confidential. The Chief Executive may elect to deal with these matters in accordance with The Society's grievance and disciplinary procedures. The same timescales as indicated in 5.2 will apply.

5.4 Written comments or complaints about the chief executive or individual trustees

Any written comments or complaints about the Chief Executive or individual trustees should be passed immediately to the Chair and treated as private and confidential. The Chair may elect to deal with these matters in accordance with The Society's grievance and disciplinary procedures. The same timescales as indicated in 5.2 will apply.

6. Recording and Monitoring

Comments and complaints are an effective way for organisations to gain feedback from their users in a constructive way. Information about comments and complaints should be reviewed by the organisation every six months.

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 as identified by our members and outlined in our plan and strategy to everybody affected by bleeding a disorder and will undertake regular impact measurements to ensure this is put into practice.
- We will ensure our service delivery is guided by the needs of members, 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.

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 practice in recruitment and employment.
- 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: We are an equal opportunities employer and welcome applications from all suitably qualified persons regardless of their race, sex, disability,

religion/belief, sexual orientation or age.

Management and governance

- We will work to reflect equal opportunities in our management and governance systems.
- Within our Board and committee structures we will seek to achieve diversity and balance of membership, to avoid any possible discrimination or exclusion.

Policy Statement on Confidentiality

The Haemophilia Society places great importance on ensuring that any personal information given to The Society is treated as confidential.

The Society needs to obtain and keep personal information on service users, donors, volunteers and paid staff in order to function effectively and provide maximum support. It is committed to ensure that personal information is collected only for specific purposes and that no more is collected than is needed for those purposes.

Personal information is only divulged within the Society to **those who need to know it** in order to provide a service. Information is stored securely either on computer or in manual records. The Society is committed to obtaining the consent of the member or service user concerned before information is disclosed outside the organisation, though in very exceptional circumstances (see para. 16) this may not always be possible. Members and other service users can have access to information which is held on them. General information and statistics gathered for planning and monitoring purposes are always anonymised.

All paid staff, Trustees and volunteers are required to conform to the Society's Code of Practice on Confidentiality and the Handling of Personal Information. A breach of confidentiality may subject a staff member to disciplinary proceedings. The Society's service users are also expected to respect the confidentiality of other service users and workers.

All staff trustees and volunteers are required to sign a confidentiality agreement and uphold this.

Code of Practice for Staff and Volunteers on Confidentiality and the Handling of Personal Information

Introduction

1. This code of practice is intended to give detailed guidance to staff, trustees and volunteers on protecting the confidentiality of personal information obtained by The Society in the course of its work. It applies to all personal information stored in whatever format, including on computer, in manual records or in our heads and the transmission of personal information in writing, by word of mouth and by computer networking.
2. Breaches of confidentiality are more likely to occur inadvertently or through well intentioned motives rather than deliberately so particular care needs to be given to what is said in public places, meetings, social settings, training courses and open plan offices and on the staircase. Equally when leaving a telephone message for a service user or volunteer, we need to think, in each instance, whether it is acceptable for us to say who we are and why we are calling - and, if in any doubt, don't! If a Society worker shares personal information about themselves on a training course, in a meeting or support group, the confidentiality of that information should be respected by all those present.
3. The code of practice applies to trustees, Chief Executive, paid staff - including temporary staff, local group members, special interest groups and volunteers. The Haemophilia Society requests that everyone continue to respect confidentiality even if direct contact with the Society ceases. The Society also expects service users to respect the confidentiality of other service users and workers. Nothing in this code of practice should be taken to override the general law.

Principles of information protection

4. The Society is registered under the Data Protection Act, which is intended to protect the personal data of individuals and their privacy. The Data Protection principles, which govern the use of personal information under the Act, are to be applied to all personal data, whether contained on computer or in manual records and it is generally regarded as good practice to do so. The principles are set out below:
 - i) Personal information shall only be obtained and processed fairly and lawfully and according to GDPR regulation. This includes explicit consent.
 - ii) Personal information shall be held only for one or more specified and lawful purposes.
 - iii) Personal information held for any purpose or purposes shall not be used or disclosed in any manner incompatible with that purpose or those purposes.
 - iv) Personal information held for any purpose or purposes shall be adequate, relevant and not excessive in relation to that purpose or those purposes.
 - v) Personal information shall be accurate and, where necessary, kept up to date.
 - vi) Personal information held for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes. (See also para 24).
 - vii) An individual shall be entitled -
 - (a) at reasonable intervals and without undue delay or expense -
 - (i) on request to be told by any information user whether he/she holds personal information of which that individual is the subject; and
 - (ii) to receive a copy of such information following a written request

(b) to have such information corrected or erased unless required to be held for legal reasons (such as financial records)

viii) Appropriate security measures shall be taken against unauthorised use of or access to, or alteration, disclosure or destruction of personal data and against accidental loss or destruction of personal data.

Definition of terms used

5. It may be helpful to define some of the terms used in this code of practice.
 - Personal information - Information which relates to an individual who can be identified from that information (or from that and other information in the possession of the recipient) including any opinions or judgements about the individual. As well as name and address this could include physical description, health, job or financial details and information about family and friends.
 - Disclosure of personal information - communicating the information in any way to an entity outside the Society.
 - Subject access - providing information to the subject of that personal information.
 - Records - all personal information, files, indexes and diaries which may be held in either computer or manual systems.

Purposes for which personal information may be collected and held

6. The primary purpose of collecting personal information is to provide services to an individual. But the Society also has to gather information for management, fundraising and planning purposes. Consent must be explicitly gained for focussed mailings and communication other than general charity updates and constitutional reasons.
7. Personal information should be collected and held only for the following purposes where consent is given, or legally required
 - provision of services, including allocation of hardship fund
 - personnel and membership administration
 - accounting and financial services
 - auditing
 - fundraising
 - supply of goods
 - planning, budgeting and monitoring
 - resource management and supervision
 - public relations and external affairs
 - investigation of complaints and disciplinary matters.
8. Information for the purpose of monitoring the provision and effectiveness of services should always be aggregated or analysed in such a way that the results aren't made available in a form which identifies individual subjects.
9. It is essential to check that if new computerised systems for collecting personal information are proposed the Society is properly registered for that purpose under the Data Protection Act and GDPR regulation.
10. The only information which should be recorded is that which is relevant to the main purpose(s) for which it is held. This information could (but need not) include:

- identification details
- personal circumstances
- social circumstances
- employment details
- financial details
- health details
- services requested or required
- details of contacts between the Society and the individual
- details of contacts between the Society and other organisations or professionals undertaken on behalf of individual service users.

Using personal information: some do's and don'ts

11. The general principle in collecting personal information should be that it is only sought for specific purposes and that it should be sufficient - but not more than sufficient - for that purpose, i.e. 'the least information required is the most information obtained'.

We should all avoid discussing members in the office. Information given by individuals is confidential and should not be passed on to other staff, trustees or volunteers, without good reason.

12. If it is necessary to divulge information outside The Society you should explain to the individual concerned the likely consequences of agreeing or not agreeing to this. You should record the subject's consent to divulge information to other agencies or parties.

Disclosure of personal information

13. Personal information should only be disclosed outside The Society if the subject has had the opportunity to refuse consent. Examples of exceptions to this rule are given below at paragraph 16.
14. If you have to disclose information, be sure that the recipient will keep the information secure and not process it for any other purpose other than that specified. You must mark letters containing personal information as confidential and send them whenever possible to a named person.
15. If you have to disclose personal information about a child, you should discuss it with him or her first, provided that the child is old enough to understand. There is no fixed age for this. You should also discuss it with whomever holds parental responsibility.
16. You may disclose outside the organisation without the subject's consent in the following circumstances:
 - i) where there is a legal obligation to do so, e.g. if instructed by a Court to provide information; and
 - ii) if, in your opinion, there is a serious risk to the health or well being of himself/herself or another individual e.g. threats of violence or actual violence or suspected or actual child abuse.

If time and circumstances allow the Chief Executive should be consulted before disclosure without the subject's consent is made. If this is not practicable they should be informed as soon as possible thereafter.

Subject access to personal information

17. Wherever possible personal information held on all records should be openly shared with the subject. Subjects are entitled to receive a copy of their information.
18. A worker who is known by the individual should explain the content and significance of the record. In no circumstances should information be tampered with in order to make it more acceptable to the subject.

Disclosure of personal information and access to subjects by researchers

19. Personal information should only be used in a way which will be beneficial to the subjects and should not cause damage or distress. The written consent of the subject should be obtained. Researchers seeking access to personal information should be required to state in writing:
 - that personal information will not be disclosed to people outside the research team;
 - that research reports will not identify any subject unless the subject has
 - specifically agreed in writing to be identified; and to describe in writing the purpose of the research;
 - arrangements made for secure storage and use of information; the precise nature of the personal information required; and
 - arrangements made as to the time and method of destruction of all material by which individuals could be identified.
 - The Chief Executives' agreement should be sought before research commences.

Disclosure of personal information and access to subjects by the media

20. The procedures set out in paragraph 20 should form the basis of contacts with the media. All requests for service users or volunteers to appear in the media should be referred to the Head of department. The names and telephone numbers of individuals must not be given to the press or media unless the individual gives explicit permission to do so.

Security of records

21. Security reviews of records held by The Society should be undertaken regularly. The Chief Executive is responsible at an operational level for maintaining the security of personal information in the Society.

Manual records - Records should not be left unattended and in out of work hours they should be locked away.

Computerised records - All workers who are authorised to have access to personal information on computers should be made aware of the importance of the secure use of passwords, file security and back-up and secure disposal of waste. VDU screens should not be located where they might be viewed by unauthorised people.

Retention and destruction of records

22. Personal information relating to service users should be retained for 7 years.
23. On request from a member records may be destroyed before that period.

Breaches of confidentiality

24. Unauthorised breaches of confidentiality will be dealt with under The Society's disciplinary procedures.

Maintaining the code of practice

25. The Chief Executive should be told about any problems arising from the implementation of this code and any suggestions for improvement. This code of practice should be reviewed 1 year after its introduction and at 2 yearly intervals thereafter.

8. Structure, Organisation and Staffing

Information available on request to trustees

- a) Organisational diagram
- b) Names of offices
- c) List of current Board Members with contact details
- d) List of members of any sub-committees

4. Finances

- a) Annual report and full audited accounts for last two years

5. Policy and Strategy

- b) Strategic Plan

Professional Advisers

Information about any professional advisors used by the organisation i.e. Solicitor, Auditor, Insurance, Investment,