



THE
HAEMOPHILIA
SOCIETY

Information pack for members interested in becoming a trustee 2019

The Haemophilia Society
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Updated 30 August 2019

For everyone affected by a genetic bleeding disorder

President: Baroness Meacher Registered charity no. 288260. Charity Registered in Scotland No SC039732.

A company registered in England and limited by Guarantee. Registered Company No. 1763614

Introduction

All full voting members of The Society (i.e. those aged 16 or over) are eligible to participate in the board of trustee election process.

There are two seats available for election in 2019 as two 'ordinary trustees' have served their full term of office. Any member is eligible to be nominated to become a trustee.

The only explicit requirements to be a trustee of The Society is that you must be a member of The Society to be supportive of our mission and strategic plan. Beyond that, we need a breadth of skills and experience across our trustees, but each individual Trustee will bring their own abilities.

Each application requires a signed nomination form and a signed Conflicts of Interest and Trustee Undertaking form. The forms and an information pack detailing the roles and responsibilities of a Trustee can be found on the website at: haemophilia.org.uk/who-we-are/workforus/ or by contacting us on 020 7939 0780.

If you are interested in standing for election as trustee, please return a complete set of nomination papers, signed by yourself and another member who is willing to nominate you to arrive at the charity's office by 5pm on Wednesday 9 October 2019.

The ballot for the election will take place between 14 October 2019 and 11 November 2019. Ballot papers will then be counted, and the results will be announced at the AGM on 16 November 2019.

Overview

Our Vision

Anyone affected by a genetic bleeding disorder has the opportunity to live a fulfilled life.

Our Mission

- Inform
- Advocate
- Empower

Our Aims

- Everyone affected by a bleeding disorder has equality of opportunity
- Everyone affected by a bleeding disorder has the opportunity to connect with others in the community
- Everyone affected by a bleeding disorder has the knowledge to feel empowered

Our Values

- Transparent
- Professional
- Pioneering
- Supportive

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The board of trustees are in the process of developing a new Strategic plan for 2020 – 2022 having consulted with members and stakeholder groups throughout 2018-19. This will be presented to members at the AGM on 16 November 2019.

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 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 both a 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 within your legal responsibilities.

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 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
- act in a fair and responsible way to any paid and unpaid staff
- make 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, GDPR, health and safety etc.

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How does the board work?

The board meets about every two months, generally in an afternoon in London on a weekday afternoon, but are aiming to meet outside London for two meetings a year. Meetings always have minutes, which are approved by the Board at the subsequent meeting.

Sub-committees

We have two permanent sub-committees – Resources and Public Inquiry (PISC) committees, and one occasional committee – Nominations. These committees make sure that specific 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. The Public Inquiry (PISC) committee looks at the work of the Inquiry, responding to Inquiry requests for information and media responses. They will also make any quick decisions required by our legal team as necessary. Nominations meet to consider major appointments such as the Chair and Chief Executive.

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

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- 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'

In July 2019 the board voted to adopt the Charity Governance Code for larger charities <https://www.charitygovernancecode.org/en/pdf> this guides the work of the board to ensure best governance practice.

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 approximately two weeks 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 Chief Executive Liz or her PA Fiona.

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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.
- Establishing 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 trustee 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 trustee 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.

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- 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 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.

<h3>Section 1: Requirements for new and prospective trustees</h3>

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

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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. This is detailed in the Scheme of Delegation.
 - 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.

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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 GDPR 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.

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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 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 them or a member of their household, more than the generality affected by the decision; they should declare the nature of the interest and withdraw from the room, unless they have 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, they should declare the nature of the interest, but may remain in the room, participate in the discussion and vote if they wish.
- If in any doubt about the application of these rules, they 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 always be expected 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.

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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.' 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.

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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>

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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 them 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 their performance.

To evaluate the performance of the Board and take steps (e.g. relating to its composition, organisation and responsibilities) to improve its performance. The board have decided to follow the Charity Governance Code to ensure its performance.

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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.

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