

**Stichting FH Europe/FH Europe Foundation (FHEF)
Rules and Regulations Version 1.1 29/06/22**

Author: John Reeve

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Our Mission

Our mission, as defined in our Articles of Association, is to improve the lives of people affected by inherited lipid disorders including Familial Hypercholesterolaemia in its heterozygous and its more serious homozygous forms, inherited elevated Lipoprotein(a) and Familial Chylomicronaemia Syndrome. These people can be patients, their families and carers, and as-yet-undiagnosed persons with these conditions, by far the largest group. We carry out a wide range of advocacy activities at the EU and national level to help change policies, regulations and clinical practices in order to improve diagnosis and treatment of these conditions and reduce their complications, as well as providing support to patient organisations in the form of awareness training, education, and sharing best practice.

The Board

The members of FHEF constitute the Board. There is a minimum of three members and no maximum number. It has overall responsibility for achieving our mission and operating in a way that complies with all applicable laws, regulations and codes of conduct. It is also responsible for the finances of the Foundation, both in terms of prudence and solvency and also of financial control, so that our income is spent only on furthering our charitable aims.

The Board is assisted in this by the Chief Executive, who is a regular attendee at Board meetings but does not have voting rights.

In addition to this oversight, the Board is responsible for:

- Setting and refreshing the Foundation's scope, guiding purpose and mission
- Setting the Foundation's high-level strategy
- Approving the strategic plan, operating plan and annual budget
- Monitoring the Foundation's performance
- Appointing the Chief Executive and setting their remuneration
- Oversight of the Chief Executive and appraising their performance
- Approving the Annual Report and Accounts for submission to the Chamber of Commerce and publication
- Appointing the Independent Examiner for the accounts
- Managing overall risk

In selecting individuals for appointment of new members, the existing members take into account the diverse skills, knowledge and experiences needed for the effective leadership and administration of the Foundation. We are committed to having a fair representation of our key stakeholders - people living with one of the conditions or caring for someone affected. At all times at least one member must be a patient or carer, but we aim to have as many such members as possible. The members aim through their interactions to increase their mutual trust and respect, and ensure equity of voice.

Members have a continuing duty to act in the interests of FHEF and to use their skills and experience to further our aims. Any conflicts of interest must be declared to the Board in a timely manner, and the member(s) concerned may not take part in any discussion or decisions on these topics, nor be part of any quorum. Members agree their objectives each year with the Chair, who appraises their performance at the year end. Another member appraises the performance of the Chair.

Members must be over the age of sixteen and of good character with no criminal record.

No member may receive remuneration from FHEF except for reimbursement of approved expenses. Members must report any income they receive related to the business of FHEF, and the Board reserves the right to ask them to return it or require them to stand down from the Board.

Members are appointed by the Board at a meeting for a term not exceeding three years. Any member may be reappointed at the end of their term until they have served for nine years. At that point they must stand down but may be reappointed after one year has elapsed.

A member may be removed by a majority vote at a General Meeting.

The Board appoints the Chair, Treasurer and Secretary. The Chair and Treasurer must be members.

Delegation of Powers

The Board delegates responsibility for operational management and day-to-day operation to the Chief Executive, who has the authority to enter into contracts for normal business activities, appoint staff and contractors, approve payments to third parties (subject to a second approval being required) and enter into such partnerships and associations that further our aims. This delegation is within agreed limits and regulated by a Power of Attorney.

The Chief Executive is responsible for delivering the mission of FHEF through:

- Drafting strategies, plans and budgets for Board approval
- Appointing and managing staff and contractors
- Raising funds and running the Industry Round Table
- Carrying out the business of FHEF including holding events, publishing material and designing and carrying out campaigns
- Supporting Board Meetings
- Managing the repository of documentation.

The Chief Executive reports to the Chair, who agrees their objectives each year and conducts their appraisal. The Chief Executive's contract can be terminated by the Board, but only according to the contract terms and any relevant legislation.

Advisory Committees

The Board and the Chief Executive can establish advisory committees to advise on specific technical issues. The current committees are:

- Scientific and Medical Advisory Committee
- Policy Advisory Committee

Operation

Our guiding principle is that the funds we raise must be used exclusively to further our charitable aims of improving the condition of those affected by the conditions in our scope and promoting early diagnosis. While we receive substantial funding from pharmaceutical companies, we are fully independent and they have no influence on our policies and strategy or the conduct of our business.

We monitor how each of our grants, sponsorships and donations are spent to ensure compliance with any conditions, such as funding for a specific meeting. This is shown in the monthly management accounts, which are reviewed in detail by the Treasurer. Annual accounts are independently examined before approval by the Board, submission to the Chamber of Commerce and publication.

For all payments there is separation of input and two approvals. Input is carried out by our accounting service and approvers are normally the Treasurer and Chief Executive, except that payments to the Chief Executive are approved by another member, as are expense reimbursements to the Treasurer.

We have an additional set of policies for key business activities.

Board Meetings

These are of two types. The Annual General Meeting (AGM) occurs once a year to approve the Annual Report and Accounts, and there are three other quarterly meetings. In addition, we normally have informal online Board update sessions twice a month, but attendance is not required, and they are not minuted unless decisions are taken.

Only the AGM is an official meeting according to our Articles of Association. This means that attendance in person is mandatory, and the quorum is two thirds of the members. Proxies are allowed to fulfil the quorum. The agenda and the text of any resolutions to be decided must be circulated two (2) weeks in advance of the meeting, and four weeks' notice of the meeting is required. The Chief Executive is invited to the meeting but does not count towards the quorum and cannot vote or be a proxy. Voting is by a simple majority, and in the event of a tie the motion is defeated.

The Board may decide on a further face-to-face General Meeting, in which case the same rules apply.

Other Board meetings are held remotely. Apart from the regular quarterly meetings, any member may call such a meeting. The agenda must be circulated seven days before the meeting, but resolutions need not be tabled in advance. The quorum is two thirds of the members and proxies are not allowed. All decisions taken at these meetings must be unanimous, including any members not present.

For more urgent matters, motions can be put to the Board by telephone or email, and are passed only if all members support the motion in writing.

Minutes are taken of each Board meeting by the secretary or, in their absence, by a Board member designated for that purpose. The minutes are adopted at a subsequent Board meeting. In addition, records are kept of all Board resolutions, decisions, or appointments regardless of whether they are made at a formal meeting.