

**Cystic**

**Fibrosis why  
we're here**

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# Section 1: Cystic Fibrosis Trust

## Welcome from the Chair of Trustees



Chairman, George Jenkins OBE

The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited for everyone affected by cystic fibrosis (CF).

Since we started in 1964, we have dedicated ourselves to promoting excellence in research and clinical care, as well as providing practical support and advice to people with CF and their families.

The Cystic Fibrosis Trust is a catalyst for change; we want to do more, discover more and achieve more than ever before. We believe that everyone with CF deserves the best quality of life and real hope for the future, with access to high-quality, specialist care.

As a Trustee, your role is critical for ensuring that the Trust is well governed, so that beating CF becomes a reality and people with CF can truly live a life unlimited. This manual contains important information about the governance of the Trust, as well as your role. I hope that you will find it a helpful source of reference.

## Governance principles

The Trust has a vision to beat CF for good, so that people with CF can live a life unlimited by this cruel condition. However, this is a demanding challenge, and will only be achieved through good governance arrangements. These arrangements, which underpin the day-to-day operations of the Trust, are set out in this document. They aim to demonstrate how the Trust is run, how it takes decisions and how it will achieve its objectives.

Underlying our governance are the Nolan Principles, which apply to anyone in a public office and form part of our code of conduct. This includes:

- Selflessness
- Integrity
- Objectivity
- Accountability
- Honesty
- Leadership

[Read more about the principles on the .gov.uk website.](http://www.gov.uk/government/publications/the-7-principles-of-public-life)  
[www.gov.uk/government/publications/the-7-principles-of-public-life](http://www.gov.uk/government/publications/the-7-principles-of-public-life)

## Legal information of the Cystic Fibrosis Trust

### Legal framework

The Cystic Fibrosis Trust is a charity, registration number 1079049 (England and Wales) and SC040196 (Scotland). It is also a company limited by guarantee in England and Wales (number 3880213) and as a Trustee, you are a Director of the company.

The Articles of Association and the Memorandum set out the purpose and powers of the Trust as seen below:

### Objects

**The Trust's objects as set out in the Memorandum and Articles of Association are to promote:**

- research into the causes of and a cure for CF and the dissemination of the useful results thereof for the public benefit,
- the care, treatment, education and advancement in such ways as are charitable of persons suffering from CF in any form, and
- the education of the general public about the causes and effects of CF.

## What does the Trust do?

**We are driven by four pledges to people with CF:**

- **Research;** to bring the best expertise and resources together to develop new drugs, treatments and evidence to improve and transform lives and ultimately beat CF for good.
- **Care and wellbeing;** to promote excellent personalised care to meet needs and focus on improving health and wellbeing wherever a person with CF lives.
- **Information and support;** to support individuals with the best information, advice and assistance, whatever a person's age and circumstance, and to help people with CF live the life they seek.
- **Engagement and influence;** to stand up for people with CF when and where it really matters and to encourage wider understanding of the impact of CF in all walks of life.

To deliver these pledges the Trust cannot work in isolation; we must work with the wider cystic fibrosis community and powerful thought leaders.

The Trust has developed a transformational strategy for the next five years, which takes the above pledges and turns them into practical themes aimed at delivering a life unlimited. The five themes can be seen below along with the fifteen programme areas which support the delivery of the theme:

Theme	Programme	The Trust's objectives (by 2020)
<b>Supporting breaths for life</b>  We will fight for healthy lungs by promoting activity, battling irreversible lung damage and increasing access to successful lung transplants.	<b>Promoting activity</b>	To ensure all people with CF have access to information about, and opportunities to engage with, regular activity to improve their health and wellbeing.
	<b>Fighting irreversible lung damage</b>	To have worked to identify pathways to delay and prevent irreversible lung damage.
	<b>Increasing access to transplantation</b>	To ensure people with CF have increased chances of receiving a transplant.
<b>Empowering young lives</b>  We will fight to bridge the dangerous gap between paediatric and adult care by engaging young people with cystic fibrosis and supporting them to make positive choices.	<b>Engage and understand</b>	To partner with young people to implement an impactful and sustainable adolescent engagement programme.
	<b>Empower and enable</b>	To enable young people to lay the foundations for a positive future.
	<b>Supporting families</b>	To ensure families of young people get the recognition, respect and support they need to help maintain their wellbeing.
<b>Making ambitions possible</b>  We will fight to help people with cystic fibrosis live life to the full, by championing personal ambitions, lifting barriers and providing support whenever needed.	<b>Achieving your ambitions</b>	To lift barriers and provide information to ensure people with CF have increased life opportunities.
	<b>Reducing the treatment burden</b>	To drive innovations to reduce the burden of care.
	<b>Improving health and wellbeing</b>	To ensure people with CF have access to the best care and support, tailored to their needs, at all stages of life.
<b>Changing lives through transformational therapies</b>  We will support vital research into transformational therapies, accelerating clinical trials and ensuring increased access when these treatments become available.	<b>Accelerating clinical trials</b>	To ensure people with CF in the UK have increased access to clinical trials.
	<b>Receiving targeted therapies</b>	To ensure people with CF have access to the best available treatments, targeted at beating their CF.
	<b>Beating CF</b>	To have funded advanced research identifying clear pathways to a cure.
<b>Harnessing the power of knowledge</b>  We will offer an unrivalled source of expertise and information to drive change and deliver maximum impact for people with cystic fibrosis.	<b>Delivering an expert knowledge base</b>	To be naturally seen as the go-to place for expert knowledge in cystic fibrosis.
	<b>Interacting with the CF community</b>	To involve people with CF in every aspect of the Trust's work.
	<b>Influencing change</b>	To have impact through advocacy; influencing decisions and affecting positive change for people with cystic fibrosis.

# Section 2: The Board of Trustees

## The role of the Board of Trustees

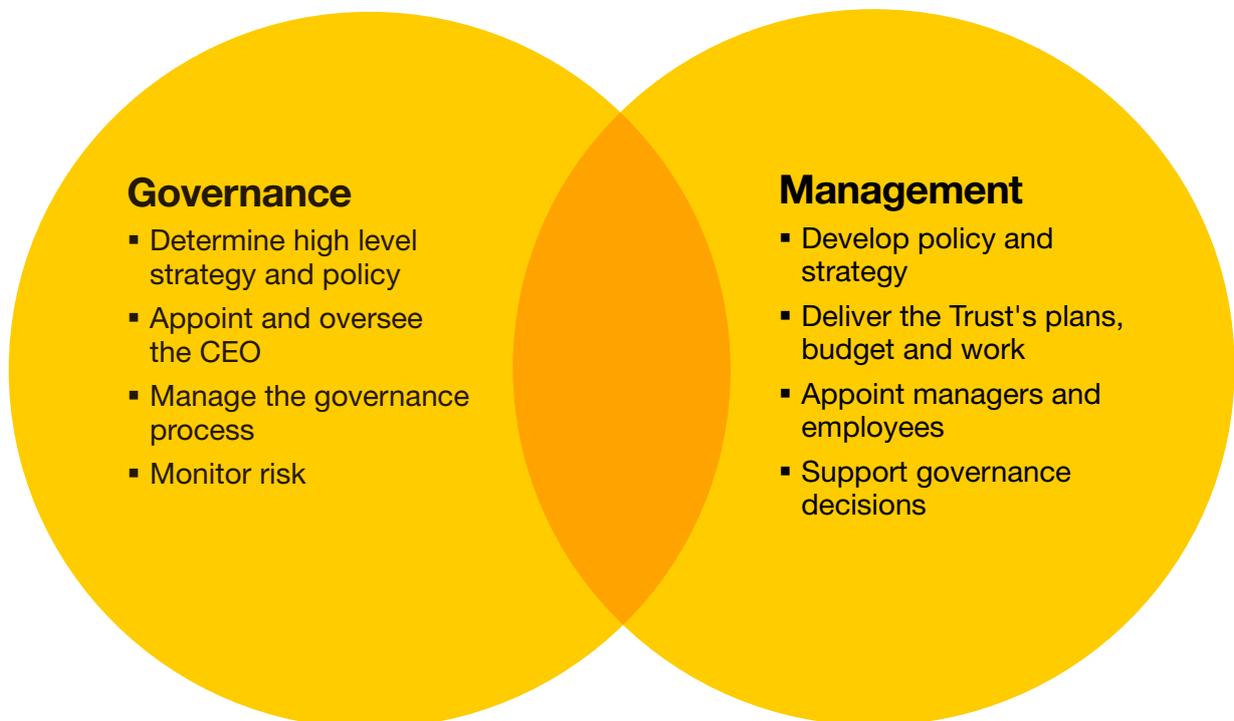
The Board of Trustees of the Cystic Fibrosis Trust is the body accountable for all aspects of the work of the Trust. The Board of Trustees are also the Members of the company as constituted in the Memorandum and Articles of Association.

**The main role of the Board of Trustees is to govern the organisation and provide overall policy direction for the Trust to achieve its aims in the most efficient and effective manner, consistent with our values and approaches. As a summary, the Board should:**

- Set the mission, vision and strategy for the Trust and ensure that these are adhered to.
- Have financial responsibility through receiving and monitoring plans, reserves and budgets, and monitoring and evaluation of the work programmes against agreed standards and targets.
- Regularly review the risks to which the Trust might be exposed, and how those risks are mitigated.

- Ensure that activities are within the Trust's stated charitable purposes.
- Ensure that the Trust complies with charity law, and with the requirements of the Charity Commission and Register of Companies.
- Ensure all Trust activities fall within the law, are compliant with relevant legislation and regulation governing its work and that appropriate reporting mechanisms are in place.
- Safeguard and protect the assets of the Trust, and ensure that charitable funds and assets are used for the purposes for which they were given to the Trust.
- Hold the Executive to account, through the Chief Executive Officer (CEO).

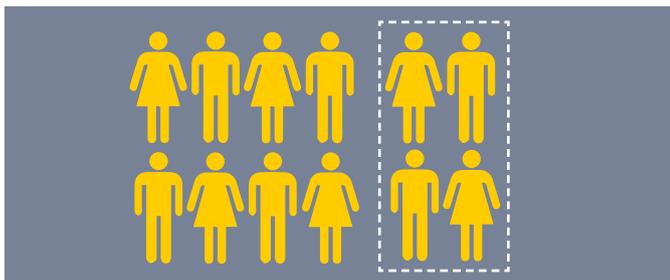
**At all times the Board acts as a body corporate and so retains ultimate responsibility and accountability for all aspects of the Trust's work. It should not however, get involved in the day-to-day operations of the Trust, as operational responsibility is delegated to the staff through the CEO. This difference can be seen below;**



There is a written delegation of authority to the Chief Executive. This can be found in the document Financial Governance Framework and Delegation of Authority. Decisions on strategic matters should be properly agreed with and reported to Trustees and clear lines of accountability maintained.

## Size and membership of the Board

The Board should have a minimum of eight and maximum of twelve Trustees.



You are appointed to serve for a period of three years, which can be renewed up to a maximum of six years. On occasion, you may be asked to serve for longer than six years, on a year by year basis (to see a process through to completion for example), but each renewal of one year should be reviewed by the Board. Three years must elapse before any retiring Trustee might be approached for service again. There is a rotation built into the terms of service to ensure continuity as well as refreshment of the Board, and to enable succession planning.

## Recruitment and Composition of the Board

The Board needs to have represented on it people who bring a range of skills, experience and perspectives required to govern the organisation effectively. The Board regularly undertakes a skills audit, where you will assess your own skills and experience against the range of skills and experience needed for effective governance. This enables the Board to identify where skills or other gaps are, which informs the Trustee recruitment process. The Board will also be informed by the succession plan which shows which Trustees will be coming to the end of their terms of service.

In proposing new Trustees to the Board, the Nominations & Development Committee will seek candidates who have the skillset that the Board has determined is needed to provide the Trustee body with a properly balanced board membership, including balance on gender, geography and ethnicity. The Nominations & Development Committee can use a variety of avenues to recruit new Trustees including public advertising. Potential Trustees will have a meeting with the Chairman and members of the Nominations & Development Committee. The Nominations & Development Committee will make its recommendations for appointment to the full Board of Trustees.

As a new Trustee, you will be given an induction which will include key documents and meeting relevant employees of the Trust. You will be asked to sign the Fit and Proper Persons form and (annually) a related party transactions declaration. You will also be able to attend relevant external courses such as those run by the NCVO as necessary.

## The role of Trustees

Your primary role is to actively participate in the governance of the Cystic Fibrosis Trust, as detailed below. You may also be asked to give individual advice to staff members or sub-committees on areas where you have particular expertise, but this should not be confused with your governance function. A job description outlining the specific duties of the Trustee is included at Appendix 1.

As an individual Trustee you have no authority to act on behalf of the Cystic Fibrosis Trust as an individual unless specifically authorised to do so by the Board of Trustees. You must be of high integrity in order that the Trust may benefit in terms of standing and influence from your reputation. A code of conduct has been developed which can be seen later on in this document and it is important that you are committed to this.

## Commitment

As a Trustee you need to be wholeheartedly committed to the Trust's vision and work. You are expected to be an advocate, positively promoting the Trust externally.

To carry out your duties effectively you are expected to commit time to study papers, preparing for and attending meetings, following up specific tasks with other Trustees, liaising with the CEO and other employees. You may be asked to sit on a committee that supports the Trust's work and you may also be asked to attend Trust events, as a representative of the Trust.

The Board of Trustees meet five times a year in addition to an Annual General Meeting. The date of the next year's meetings will be agreed at or by the November meeting of each year. Notice of the Annual General Meeting must be sent out to all Trustees not less than 21 days before the meeting. You should make every effort to attend all Board meetings, and should notify the Chair and CEO if you are unable to attend.

Other meetings may be called by the Chair if, after discussion with the other Officers and CEO, and feels there is sufficient business to warrant a meeting.



## Board Meetings

An agenda and relevant background papers will normally be circulated five working days before the meeting. It will be made clear whether items are for decision, information or discussion. If you wish to have a specific item included, then you should discuss with the Chair who will make the decision whether it is included and when.

You should bring a fair and open-minded view to all discussions of the Board and should ensure that all decisions are made in the Trust's best interests.

You are expected to foresee and avoid any conflict of interest (see the code of conduct). Where one arises, you are expected to declare the interest (see the code of conduct) and if the Board requires it, to absent yourself from any discussion or vote taken on the matter. Any transaction under which you benefit either directly or indirectly must have proper legal authority.

Confidential information or material (relating to partners, donors, employees, commercial business etc) provided for, or discussed at a Board meeting should remain confidential and within the confines of the Board and should not be discussed outside the Trustee body.

The CEO will be present at Board meetings unless the meeting is discussing his/her annual performance review, terms and conditions, or remuneration. The other Executive Directors are normally present at Board meetings unless the Chair and the Chief Executive request otherwise. Other employees may be invited for specific items. The CEO and other employees do not vote.

Other guests may be invited as presenters or observers for specific agenda items or for the whole meeting at the invitation of the Chair. Guests may also not vote at Board meetings.

The Trust's official position on any matter is agreed by the Board and then articulated by the Executive team.

Minutes of the meeting will be sent to all Board members. Only decisions recorded in minutes are decisions of the Board. The minutes are approved at the following meetings (after any queries have been dealt with) and will then become the official record of action.

The Board reviews its own performance on an annual basis, and will review the performance of the Chair.

## Making decisions

The Board aims to make decisions by consensus. Where a vote is required, decisions shall be made by a majority of votes. In the case of an equality of votes the Chair shall have a second or casting vote. The quorum for the transaction of the business of the Trustees may be fixed by the Trustees but shall not be less than one-third of the number or two Trustees, whichever is the greater.

### Trustee expenses and remuneration

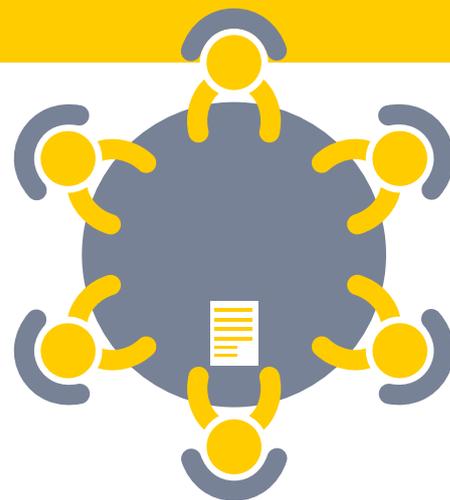


You are not remunerated for your service to the Cystic Fibrosis Trust and this is a voluntary position.

On occasions the Trust may want to engage you for your professional services for an agreed rate of remuneration. Any arrangement of this kind will be recommended by the CEO but needs the full agreement of the Board on a case by case basis, and may have to be referred to the Charity Commission. All Trustee remuneration must be reported in the Annual Trustee's Report.

You can be reimbursed for the direct costs incurred in relation to your duties as a Trustee according to the Trust's expenses policy. All receipts must be produced with the claim. Trustee expenses will be declared in the Annual Trustee's Report.

You may occasionally receive a gift, benefit or an offer of hospitality arising from your position as a Trustee. It is suggested that any item considered to be of significant value is declared to and recorded by the Company Secretary and the register is available for the Board to review. You should ensure that it is not seen to reasonably compromise your judgement or integrity or place you under an obligation to those individuals or organisation.



## Trustee liability

You are indemnified out of the assets of the Trust against all costs, charges, losses, expenses and liabilities which you may sustain or incur or about the execution of your duties of office. However, this excludes liabilities arising from any potential criminal acts as that would be contrary to public policy.

You are unlikely to be personally liable as long as you have acted prudently, and the Trustee insurance protects you in the rare case where you might be shown to be liable.

You are insured for any claim of wrongful act. A wrongful act is any actual or alleged breach of duty, breach of trust, neglect, error, misstatement, omission, breach of warranty of authority, libel and slander or any other act committed by any insured solely in the course of the activities of the entity. This is up to £5,000,000 in the aggregate.

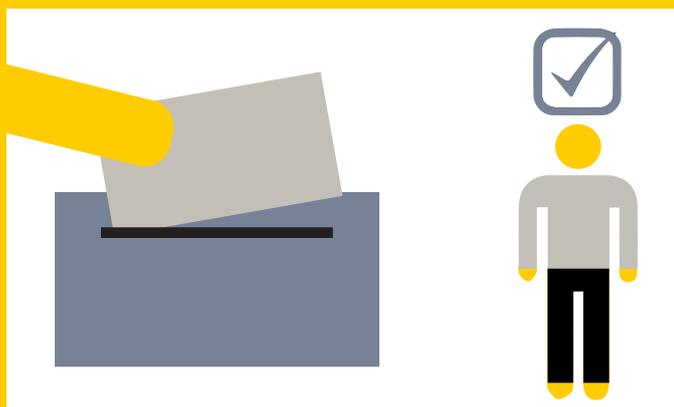
## Election of Officers

The Board has three Officer positions; Chair, Vice Chair and Honorary Treasurer. These are appointed from within the Board, although Board Officers may on occasion be recruited specifically for their skills relevant to the role, and invited on to the Board to fulfil that role.

The election of Officers is recorded in Board meeting minutes. Officers are recruited for the remainder of their period of service on the Board, unless they choose to stand down earlier.

The descriptions of these roles can be seen in Appendix 1.

The Board may also appoint a President, Vice-President(s), a Patron and Vice-Patron(s) of the Trust. Such appointments should be at the discretion of the Board and for such time and on such conditions as the Board may decide. Any such person may be removed at any time by simple majority vote of the Board and shall have no right to speak or vote at the meeting of the Board or the Trust.



## Leaving the Board of Trustees

There are a number of reasons why you may have to step down as a Trustee or no longer be able to hold office. These are outlined in article 50 of the Articles of Association. This may also be if you are unable to commit as required or are unable to attend a number of meetings and therefore contribute effectively to the Board. You may also be removed as a Trustee by an ordinary resolution of the members

You are entitled to an exit interview once you have completed your term of service on the Board and are either retiring at the end of your term or resigning earlier. Exit interviews will be conducted with either the Chair or Vice Chair. This interview is an opportunity for you to reflect on your experience of being a Trustee and offer insights to improve the governance of the organisation.



# Section 3: Other governance structures and delegated responsibility

The Board has constituted a number of committees to enable it to efficiently exercise its full remit. Unless explicitly stated in the terms of reference for any committee, the responsibility for the work of all the committees is not delegated; the responsibility for decisions taken in committees rests with the full Board.

Having committees enables the Board to exercise its responsibilities over the details of the Trust's work, while still retaining authority and responsibility at the full Board. To do this the Board needs clear procedures:

- The Board retains responsibility for the work and decisions of committees at all times unless authority has been explicitly delegated.
- Where authority has been delegated to a committee or working party, the full Board still needs to be aware of the decision taken in its name
- The Terms of Reference for each committee are agreed by the Board and can only be amended by the Board
- The Board decides membership of committees. Committees can suggest names for the Board to consider
- The Committee Chair is appointed by the Board and serves for a period of three years (which can be renewed once)
- The Chair and Vice Chair of the Board of Trustees are ex-officio members of every committee and may attend at their discretion

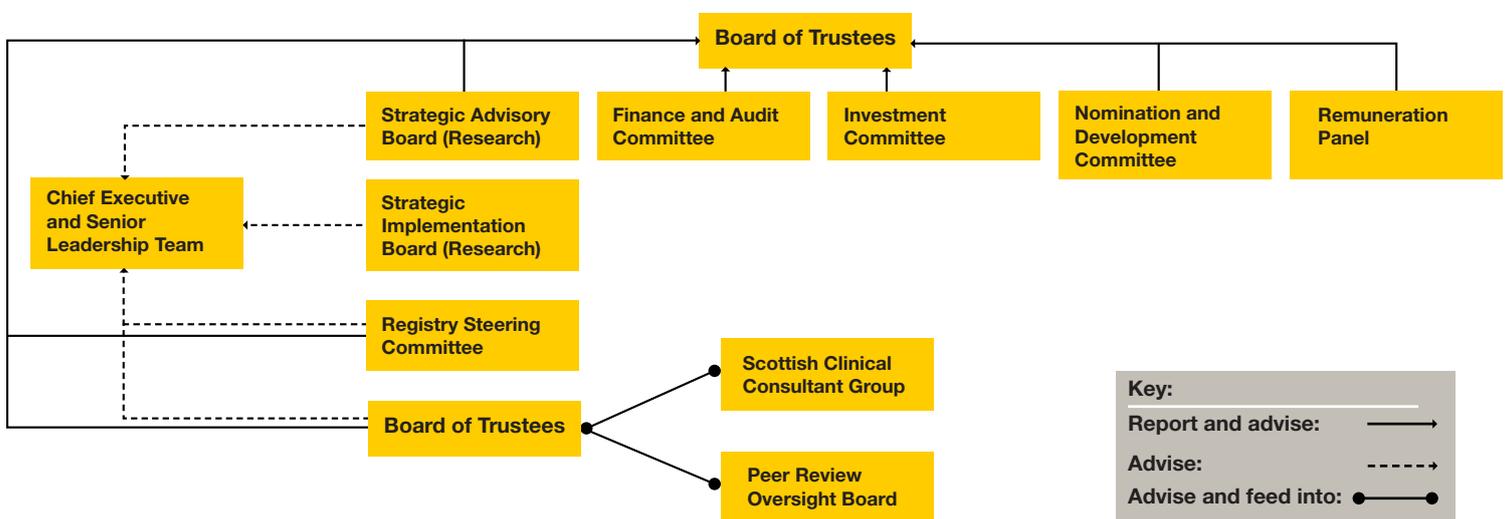
- Each committee is serviced by a named Executive Director of the Trust and can be attended by the Chief Executive either at his/her discretion or by the Committee Chair's request
- Committees are accountable to the full Board usually through the committee chair or relevant Trustee on the committee

The full Board needs to be aware of the decisions taken in committees and the advice being offered by the committee to the Board. To facilitate this, minutes of committee meetings are made available to all Trustees with the agenda and papers for the subsequent Board meeting.

## Current committees

The structure of this can be seen below and full terms of reference are available. This also includes committees and boards which advise the Executive directly:

- Finance and Audit Committee
- Investment Committee
- Nominations & Development Committee
- Remuneration Panel
- Registry Steering Committee
- Strategy Advisory Board
- Strategy Implementation Board
- Clinical Advisory Group
- Registry Steering Committee
- Peer Review Oversight Board
- Scottish Clinical Consultant Group



## Section 4: Code of Conduct, Conflict and Declaration of interest

Trustees are the custodians of the governance process and ultimately liable for ensuring that the Trust is effectively administered. Through your collective actions as Board, you are also responsible for the successful development and delivery of a strategy to further the objects of the Trust.

The code establishes the principles expected of you as a Trustee in order to fulfil these responsibilities by:

- maintaining the highest standards of integrity and stewardship,
- ensuring that the Trust is effective, open and accountable, and
- ensuring a good working relationship with the Executive.

It provides guidance on how to ensure that your actions and behaviour are consistent with the Trust's values and the high standards of conduct required to maintain confidence in the Trust and its work.

It is not a list of Trustees' legal duties, although is fully consistent with legal principles and that of the Nolan Principles.

### As a Trustee of the Cystic Fibrosis Trust you will:

- Act in accordance with applicable company and charity law.
- Act with probity, due prudence and should take and consider professional advice on anything in which the Trustees do not have expertise themselves.
- Administer the organisation and all its assets in the interest of its beneficiaries.
- Strive to avoid any conflict of interest between the interests of the charity, and personal, professional, and business interests (see below).
- Make decisions together and take joint responsibility for them. The extent to which any one Trustee or small group of Trustees is empowered to speak for or take action on behalf of the Trust or the Board is a matter for all Trustees to decide together. Such decisions should be recorded.
- Accept that in fulfilling your role as a Trustee of the Cystic Fibrosis Trust your responsibility should be solely to the Trust and you will focus the expertise you bring from other spheres of your life for the benefit of the Trust.

- Ensure that you have sufficient time to attend meetings and to discharge effectively the other duties reasonably expected of you.
- Uphold high standards of courtesy and respect in the business, following both the Nolan principles and the Trust's own value and behaviours. You should not engage in any behaviour towards any person which might reasonably be interpreted as discriminatory, bullying or harassment.
- Take all appropriate steps to safeguard information given to you in confidence or which otherwise comes into your possession in circumstances where confidentiality arises. You may give such information to other Trustees, unless that Trustee has a conflict of interest which makes inappropriate for them to have access to the information.
- Uphold and promote the Trust's values, objects and policies when representing the Trust. You should not represent yourself as speaking officially for the Trust to the media, unless otherwise agreed.
- Maintain a constructive, professional relationship with employees based on a sound understanding of respective roles and based on mutual trust and respect. You should recognise that employees are part of a line management structure responsible to the Chief Executive, and not to any Governance Body other than the Board, nor to individual Trustees. You should not place employees in any position where this principle might be compromised nor should you make onerous or repetitious requests for information. Ideally this should be fed through the Chair of Trustees and form part of an agenda item for the relevant meeting.



## Declaration and Conflict of Interest

Legally you have a duty of care to act in the best interests of the charity. This is reinforced by the Trustee Act 2000, which states you must exercise such care and skill as is reasonable in the circumstances. In making decisions, you should take into account the background information provided, and the views expressed in the meeting, and must exercise independent judgment and not allow any private interests or commitments to influence your decisions, which should always be in the best interests of the charity.

**It is therefore the responsibility of each Trustee to be aware of potential conflicts of interest between themselves and the Cystic Fibrosis Trust.**

A conflict of interest or loyalty arises where your personal interest or loyalty, or the interest or loyalty which you owe to another individual, organisation or body, arise at the same time. The Board must manage any situation where you have the potential to benefit personally from your position as a Trustee or is influenced by conflicting loyalties. Interests can be financial or non-financial and direct or indirect (detailed below).

It is also recognised that many Trustees join the Board because of a direct link to the condition. You should be aware of any emotional or personal response which may impact upon or conflict with your duties as a Trustee.

You must put the best interests of the Trust first at all time; this duty overrides all other considerations.

You should strive to avoid any conflict of interest. This includes avoiding actual conflicts of interest as well as the perception of conflict of interests.

You should be aware of any potential conflicts of interest that might arise for you, and declare them either at the start of a Board meeting or as soon as such conflict becomes evident. Where such a conflict of interest is declared, you may be asked to withdraw from the discussion and decision of the relevant item on the agenda.

You will also be asked when you join and annually to complete a related party transactions form.

## Examples of conflicts of interest



- **Direct financial gain or benefit** – examples include payment for a service (eg legal), the award of a contract to another organisation in which you have an interest and from which you will receive a financial benefit or the employment of a Trustee within the charity, even when you have resigned in order to take up employment.
- **Indirect financial gain** – examples include employment by the charity of your spouse or partner, where your finances are interdependent.
- **Non-financial gain** – for example where a user of the charity's service is also a Trustee. It is important that such users are involved in the decision making and governance of the Trust and as such you may still be able to take part in decisions depending on the circumstance and given the interest is declared at the outset.
- **Conflict of loyalties** – examples include being appointed by the local authority, another charity or by one of the charity's funders, or where your friend is employed by the charity. Where you are elected, or appointed, by a connected organisation or other third party, you must act only in the best interests of the Trust in carrying out your role.
- **Emotional interest** – for instance having a dependent who would be eligible for a potential drug coming on to the market, and therefore you would have more interest in supporting decisions relating to the drug. Whilst emotional interests cannot always be put aside, you should be aware of any immediate conflict and declare it as soon as possible.

# Appendix 1: Role descriptions

## Trustee role description

### Statutory duties

- To ensure that the Cystic Fibrosis Trust complies with its governing document, charity law, company law and any other relevant legislation or regulations.
- To ensure that the Cystic Fibrosis Trust pursues its objects as defined in its governing document.
- To contribute actively to the Board of Trustees' role of giving firm strategic direction to the organisation, setting overall policy, defining goals, setting targets and evaluating performance against agreed targets.
- To ensure that the organisation uses its resources exclusively in pursuance of its objects; the organisation must not spend money on activities that are not included within its own objects, no matter how worthwhile or charitable those activities may be.
- To safeguard the good name and values of the Cystic Fibrosis Trust.
- To ensure the effective and efficient administration of the organisation.
- To ensure the financial stability of the Cystic Fibrosis Trust.
- To protect and manage the property of the Cystic Fibrosis Trust and to ensure the proper investment of the charity's funds.
- To appoint and support the Chief Executive and monitor his/her performance.

### Other duties

In addition to the above duties, Trustees should:

- Be an ambassador and advocate for the Cystic Fibrosis Trust.
- Be willing and able to use any specific knowledge or experience he or she may have to help the Board of Trustees reach sound decisions. This will involve scrutinising Board papers, leading discussions, focusing on key issues and providing advice and guidance requested by the Board or the Chief Executive in areas where the Trustee might add value and insight to deliberations.
- Follow the Governance Manual and current best practice on being a Trustee at all times.
- Be an active member of the Trustee body in exercising its responsibilities and functions, and attend meetings faithfully.
- Maintain good relations with the staff team; sit on appraisal, recruitment and disciplinary panels as required.



## Chair role description

This role description sets out the specific responsibilities of the Chair and should be read in conjunction with the role description for Trustees of Cystic Fibrosis Trust, which gives the overarching responsibilities and the person specification for all Trustees.

### Main responsibilities

- To lead the Trustee body in ensuring that it fulfils its responsibilities for the governance of the organisation by ensuring that the charity acts in accordance with its constitution and by managing its activities.
- Chair regular meetings of the Board of Trustees, agreeing the agenda with input from the Chief Executive and the Company Secretary.
- Work in partnership with the Chief Executive, helping him or her achieve the mission of the organisation.
- Promote the interests of the Cystic Fibrosis Trust across all parties in its constituency, including maintaining outside contacts with Government and with the Chief Executive and act as a spokesperson for the Cystic Fibrosis Trust;
- Ensure that the Board of Trustees is kept properly informed on all important matters, including senior executive remuneration, corporate governance and strategy.
- Ensure that strategies, plans and policies are initiated for agreement by the Board of Trustees, and that such plans are put into effect by the Chief Executive.
- Ensure that the performance of senior executives and the Board of Trustees as a whole, and its committees, is evaluated on a regular basis.
- Ensure, in conjunction with the Nominations & Development Committee, the appropriate membership of the Board of Trustees, with particular reference to long-term succession and balance of skill sets.
- Make recommendations to the Board of Trustees on appointments to the Board's committees, ensuring that committee membership is refreshed from time to time and that undue reliance is not placed on a particular individual.
- Be available for discussion with any member of the Board of Trustees, act as the Trust's arbitrator on internal differences of opinion and maintain contact with the executive.
- Promote constructive relations between the executive and the Trustees and chair at least one meeting per year attended only by Trustees to discuss the Chief Executive's appraisal and remuneration.

## Honorary Treasurer role description

This role description sets out the specific responsibilities of the Honorary Treasurer and should be read in conjunction with the role description for Trustees of Cystic Fibrosis Trust, which gives the overarching responsibilities and the person specification for all Trustees.

### Main responsibilities

- On behalf of the Board ensure that the Cystic Fibrosis Trust's financial obligations are met.
- Ensure the Trust operates within the legal and financial guidelines set out in current legislation.
- Ensure that adequate financial controls are in place and that the organisation operates within a sound financial framework.
- Work with and support the Director of Finance & Resources in order to be satisfied that the financial information presented is comprehensible, accurate and timely.
- Chair the Finance Committee in line with standing orders and terms of reference, and report back to the Board of Trustees.
- Ensure that grants and other funds received for specific purposes are appropriately spent.
- Ensure financial risks facing the organisation are identified and recommend appropriate action.
- Advise the Board of Trustees on the financial implications of its strategy and policy objectives.
- Work with the auditors to formally present the accounts to Trustees, drawing attention to important points in a coherent and easily understandable way.
- Oversee the process of appointment of auditors; ensure that the charity has appropriate reserves and investment policies;
- Keep the Board informed about its financial duties and responsibilities;
- Ensure the organisation's compliance with legislation and charity financial regulations.

## Chief Executive role description

Reporting to: The Chair and through him/her to the Board of Trustees

### Main job role

- Formulate and give direction and leadership to the achievement of the Trust's philosophy, objectives and strategies and to its annual targets.
- Be responsible for the management and administration of the Trust in the execution of the Board's policies.
- Together with the Chairman, enable the Board to fulfil its functions and to ensure that the Trustees receive appropriate advice and information on all relevant matters.
- Lead and manage the organisation.
- Ensure that the Trust has a long-term strategy to enable it to achieve its objectives. To monitor and review this strategy on a regular basis.
- Provide leadership to the Senior Leadership Team.
- Make certain that the Trust's corporate philosophy and policies are consistent, pertinent and practised through the organisation.
- Direct, coordinate and keep under review the work of those members of the Trust reporting directly to him/herself.
- Ensure that the Trust has the resources (human, material, financial) to make steady progress towards the achievement of its objectives.
- Establish and maintain an effective system for the recruitment, management, training and development of staff and volunteers to achieve the Trust's objectives and to implement its strategy.
- Foster good communications throughout the Trust and, in particular, maintain close and constant communication with the Trust's dedicated Branch and Group Volunteer network in conjunction with its Regional Managers structure.
- Maintain a climate that attracts, retains and motivates top-quality people.
- Ensure that there is a clear policy on relations with the media, and service the spokesperson(s) for the Trust.
- Ensure that the Trust is represented in a professional manner to its various audiences. Duties will include the representation and/or lobbying of specific policy areas and issues such as research, family support and cystic fibrosis adult needs, in conjunction with the Chair and other influential parties.

- Ensure that the necessary resources are provided and proper standards maintained for the protection of the Trust's people and assets, giving particular attention to:
  - legal requirements,
  - health and safety at work, and
  - maintenance and security of property.
- Report periodically to the Board on the progress of the Trust's work, together with any matters that are relevant to the discharge of the Board's responsibilities.

### Serving the Board in consultation with the Chair:

- Recommend for the Board's approval an annual calendar of meetings for both the Board and the Finance Committee together with other important meetings and events.
- Ensure that items requiring the consideration of the Board are placed on the agenda of its meetings as appropriate.
- Report periodically to the Chair and the Board as appropriate on the progress of the Trust and on all other matters relevant to the discharge of the Board's responsibilities.
- Assist the Chair in obtaining the appropriate level of input and involvement of each member of the Board and to arrange for briefing sessions, sub-committees etc to take place as necessary.
- Where appropriate, monitor and make recommendations on the composition of the Board and other committees.
- Ensure that an annual budget is prepared and submitted to the Finance Committee for the approval and recommendation to the Board.
- Ensure that expenditure is controlled in line with the annual budget as approved by the Board and to be responsible to them for the overall health of the Trust.
- Coordinate the funding strategy and requirements of the Trust relating to the direction of research and clinical support needs and priorities.
- Foster good relations with governments, statutory and voluntary bodies. This will entail, as required, an active participation with appropriate 'umbrella groups' in the sector, involvement with the relevant international organisations and the representation of the Trust's interests to Government and other national bodies.
- Ensure that the Trust discharges its constitutional and legal obligations

# Cystic Fibrosis Trust

**[cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)**

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