

# Applicant Information Pack

**Trustee – Treasurer**

June 2025





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## Letter from the Chair of Trustees

Dear applicant,

Thank you for your interest in the role of  
Trustee – Treasurer, at The Marfan Trust.

We are a small national heart charity expanding rapidly, with 7 faithful Trustees who know about this inherited heart disease, Marfan syndrome. We need an 8th Trustee with financial expertise to guide our future, using our sizeable reserves wisely. A pleasantly paced role, working with motivated, talented staff, awaits. It involves liaising with our bookkeeper, and auditor, CAF Bank, our 4 staff, and fundraiser. Would you like to give back to the community by helping our 3700 UK families live longer, healthier lives? To view our output please see our website [www.marfantrust.org](http://www.marfantrust.org). We look forward to meeting you.

We hope the information in this pack will tell you enough about us for you to decide whether to apply. If what you read appeals and you would like to come and join with us on our journey, then we look forward to receiving your application.

If you would like more information about this Trustee/ Treasurer role, you can contact Suzie Leveson of Action Planning's Recruitment Team, who is managing the recruitment process for us at [suzie.leveson@actionplanning.co.uk](mailto:suzie.leveson@actionplanning.co.uk)

Thank you again for your interest in supporting the Marfan Trust with your skills in this way.

Kind Regards,



**Anne Child MD FRCP**  
Chair & Medical Director of Marfan Trust  
Senior Research Associate, Imperial College



## ABOUT THE MARFAN TRUST



Marfan syndrome is an inherited disorder of the body's connective tissue that leads to medical problems affecting the heart, eyes and skeleton, requiring treatment to prevent life-threatening complications.

It affects men, women and children of any race or ethnic group. Over 18,000 people are affected by Marfan syndrome in the UK, and many of these are undiagnosed. It was identified in 1896 by French physician, Antoine Marfan.

Founded in 1988 to fund research into the cause, treatment and possible prevention of Marfan syndrome, the Marfan Trust is the only Marfan charity in the UK. The Marfan Trust is a London based charity, which serves 3700 UK families suffering from this unusual familial heart disease. The staff have seen the average age of death from Marfan rise to 68 through their extensive work.

The Trust is also committed to supporting those with Marfan syndrome and their families and raising awareness of the condition, so that more people recognise the signs and more diagnoses are made in good time. This is crucial as over 18,000 people are affected by Marfan syndrome in the UK, with many more anticipated to be living with the condition undiagnosed. In 2019, the Trust merged with the Marfan Association (MA) following the MA's closure.

Originally located at St. George's University London, in 2019 the Trust moved to new headquarters in the Guy Scadding Building, Chelsea, hosted by Imperial College, London, before settling in Keston, Kent.

The Marfan Trust's three main objectives are to:

- Provide support and medical guidance to those affected and their families;
- Provide educational literature on Marfan syndrome and all its aspects to the medical profession and the general public, thus raising awareness of the condition; and to
- Fund medical research projects that aim to aid the diagnosis and treatment of Marfan syndrome patients.





### Since it was founded, the Marfan Trust has:

- Funded the establishment and running of the Sonalee Laboratory dedicated to research into Marfan syndrome.
- Formed an international consortium to identify the Marfan gene (fibrillin-1) in 1991, permitting family screening for the first time. This is now an internationally used standard diagnostic tool.
- The Trust also funded a research fellow who made a major contribution to the discovery of fibrillin-1
- Established the first UK laboratory to provide research reports of 100 gene mutations. As a result, a diagnostic test is now offered through the NHS, and available to everyone in the UK.
- Co-funded the successful six year Aortic Irbesartan Marfan Study (AIMS) trial together with British Heart Foundation and the Marfan Association.
- Discovered new genes for each of Ectopia Lentis (EL), Scoliosis and Familial Aneurysm (LMOD 1). These discoveries will help distinguish these conditions from Marfan syndrome.
- Established a national UK research database of patients and families which provides vital data for current and future ethically approved research projects.
- Helped set up 24 national regional Marfan clinics in the UK, now in major NHS hospitals to provide local diagnosis, management and care so people do not need to travel long distances.
- Provided a helpline for national and international enquiries from patients, family members, doctors, dentists, referring physicians and paramedical personnel.
- On an annual basis, taught three funded summer medical studentships and four BSc/MSc students on laboratory research so more future medical professionals understand and are aware of Marfan syndrome.
- Raised £120,000 per year from donors to provide research, education and awareness of Marfan syndrome.
- Provided research updates and practical advice via multiple communications: two paper newsletters a year plus frequent e-communications and social media posts, educational publications, videos, webinars and drop in clinics to 5,000 plus supporters.
- Published 170 papers in scientific journals and chapters in books, and presented the Trust's work at international conferences where the scientific community comes to debate and share ideas.
- Amalgamated the Marfan Association's (MA) Legacy from 2019, adding 1,700 new supporters to the Trust.



## Current and future research projects include:

- Studying cells from patients to test new medications to improve fibrillin protein production - a collaboration with Cambridge University to find out what medications may be even more effective in preventing aneurysms;
- **Publishing the Marfan genotype – phenotype correlations**  
This project will enable us to work out how the position and type of gene error can predict the severity of Marfan syndrome and therefore guide patients and doctors on how to better manage treatment;
- **Discovering new genes for Familial Thoracic Aortic Aneurysm and Dissection (FTAAD)**  
A UK collaborative project leading to clearer diagnosis and more specific care, as well as family screening;
- **Searching for new genes for Ectopia Lentis (EL).**  
A European collaborative project that enables doctors to distinguish EL from Marfan syndrome; two new genes have been published;
- **Publishing two Adolescent Scoliosis genes.**  
A collaboration with University of Montreal Canada which will allow for correct genetic counselling and distinguishing Scoliosis from Marfan syndrome; the first two genes have been published;
- **Creating zebrafish models of structural genetic aortic disease.**  
Heart disease genes will be introduced into transparent fish so the development of an aneurysm can be observed. This will lead to better understanding of how aneurysm genes produce abnormal development;
- **Searching for modifying genes for Marfan syndrome.**  
This collaborative project will enable finding minor genes which alleviate the effect of the Marfan gene to be harnessed to improve the condition;
- **Using whole genome sequencing to discover new genes for hypermobile Ehlers Danlos syndrome (hEDs)**  
hEDs overlaps with Marfan syndrome. This process will allow us to differentiate hEDs from Marfan syndrome and provide correct management; hEDs has no known genes at present. Families are under active investigation; and
- **Surveying the quality of life for young people with Marfan syndrome.**  
Physical and psychosocial impact of Marfan syndrome on lifestyle needs to be better and more widely understood. We are preparing a state-of-the-nation snapshot survey to be taken of the physical and psychological manifestations of Marfan syndrome, especially fatigue and pain.

## ABOUT THE ROLE



As a Trustee, you will help steer the charity's strategic direction and ensure it continues to meet its charitable objectives and governance responsibilities in line with charity law. This is a meaningful opportunity to support a cause that directly impacts the quality and length of life for individuals with this complex condition.

This is a unique opportunity to lend your professional expertise to a small but impactful charity from the comfort of your home. You'll join a passionate, collaborative team, and help shape the future of Marfan support, education, and research in the UK. In return, you'll gain the satisfaction

of knowing your time and skills are directly helping to improve lives – with limited time demands and maximum impact.

The Marfan Trust welcomes applications from a wide range of backgrounds that are reflective of the full diversity of its community. We would encourage candidates with current or previous experience in the charity sector. We would be particularly interested to hear from individuals with a background in Strategic Financial Management.

This role is voluntary and therefore unpaid. However, reasonable expenses will be reimbursed.

## Time Commitment

The role may take up to 3 – 4 hours per week to keep on top of the organisations finances and accounts and to attend relevant meetings and liaise with staff and funders. There are quarterly Trustee Board meetings that take place in the evening and are held remotely. We are looking to move to meeting face to face at least once a year also.

There will also be the occasional fundraising event that we would hope our Trustees would be able to support and attend.

**Trustees are appointed for 3 yearly terms with an option to serve for a second three year term.**

## What we are looking for in a Trustee/Treasurer

- Experienced Chartered Accountant with a willingness to share these skills voluntarily ensuring the financial health of the Trust.
- Good experience and knowledge of Charity finance, governance and compliance.
- A genuine interest in rare diseases, particularly those affecting the heart or eyes.
- Ability to provide support to the finance staff and clear direction to the Trustees on financial matters.
- Sound judgement and the ability to seek and challenge information to enable the decision making process.
- Ability to assimilate and analyse information quickly in order to debate issues at strategic levels.
- Ability to create and nurture strong relationships with Marfan Trust supporters and funders.

## KEY RESPONSIBILITIES



- To ensure The Marfan Trust complies with its governing document, charity law, company law and any other relevant legislation or regulations.
- To ensure The Marfan Trust uses its resources exclusively in pursuance of its objectives.
- To actively contribute, together with other Trustees and the staff team, to ensure there is clear strategic and financial direction of the Trust.
- To be an ambassador for The Marfan Trust, safeguarding and developing its positive reputation and its values.
- To ensure the long term financial stability of The Marfan Trust.
- To protect and manage the financial assets of The Marfan Trust.
- To partake in appropriate training and personal development as and when required for the role.
- To provide support for elected staff with the Trust.
- To approve/authorise payments as and when they are submitted,
- To be the finance conduit with the Trusts' accountant, trustees, staff, auditors, sponsors, investment advisor, fundraiser, other similar charities, Charity Aid Bank and Charity Commission.
- To actively contribute to the Board of Trustees, using financial skills, knowledge and experience to aid decision making.
- To adhere to The Marfan Trusts policies and procedures,
- To support the work of The Marfan Trust in practical ways as and when required.





## PERSON SPECIFICATION



### Essential:

**Professional Knowledge** – Chartered Accountant

**Experience** – Extensive experience of working as part of an organisation of a similar scale to The Marfan Trust and working within a Trustee Board. Excellent working knowledge of accountancy and book keeping.

**Communications** – Able to communicate effectively, with clarity and persuasiveness on key financial issues to non financial people, both face to face and in writing.

**Strategic Awareness** – Ability to analyse the big picture of the Trusts finances and accounts, identifying the threats and opportunities for the long term continued work.

**Fundraising** – Knowledge of (or capacity to develop knowledge of) fundraising and income generation.

**Collaborative Working** – Contributing effectively within the Trustee Board and wider team not just within the remit of finance but also the overall work of The Marfan Trust and helping in areas outside finance when needed.

**Planning & Organisation** – Anticipating possible demands, and outcomes of situations/projects and plans and is able to aid the Trust in prioritising accordingly.

### Desirable:

- Previous work experience with medical charity.
- Good knowledge of Charity Law.
- Experience of working in a leadership role.
- Working knowledge of how to manage investment portfolios.

## HOW TO APPLY



Expressions of interest should be sent to Suzie Leveson at:  
suzie.leveson@actionplanning.co.uk

Please enclose:

- A full CV outlining your career history to date. Please include any Trustee Board/Treasurer experience to date.
- A covering letter, of no more than two pages in total, **outlining how you meet the criteria set out in the person specification and your reasons for applying.**
- A completed Personal Details Form – available on the Action Planning website.

**The closing date for applications is 9am on Friday, 4th July 2025.**

All applications will be considered immediately after the closing date and candidates informed if they have been shortlisted for first interview by **5pm on Monday 7th July 2025.**

First interviews will be conducted by Suzie Leveson, HR Consultant, Action Planning using Zoom during week commencing **7th July 2025.**

Second interviews will be held in person towards the end of July with Dr Anne Child, Chair of Trustees, Robin Randall, Trustee and Suzie Leveson, HR Consultant, Action Planning.