

Trustee: Application Pack

KEY DETAILS

Job Title:	Trustee
Working with:	The wider board of trustees, and the CEO

BACKGROUND

Findacure is a UK charity that is radically transforming the world's understanding of rare diseases. Our vision is a world in which all rare diseases have treatments – made together with patients, for patients. Findacure positively **transforms the lives** of people affected by rare diseases and **accelerates change** in the field by:

- Working directly with **patient groups** to **empower** them, giving them the skills to professionalise their work, and the confidence to recognise their own expertise in their conditions.
- Building a rare disease community** that supports, informs, and collaborates together for the betterment of all rare conditions.

You can find more information about the charity, our history, our team, and our current trustees on our website: www.findacure.org.uk/about-us/

Findacure is a registered charity in England and Wales (number 1149646) and a private limited company (number 8174973). You can find our annual accounts on the charity commission website.

OVERVIEW OF THE ROLE

Findacure is entering a new stage of its development. We are looking to grow the charity, unify our patient empowerment projects, and attract more large and long term grants to build our sustainability. This shift should allow us to increase our ability to plan our projects in the long term, to more rapidly respond to the needs of our patient beneficiaries, and to develop more collaborative projects with the wider rare disease community.

Findacure's trustees work on a voluntary basis to oversee the management, finances, and strategy of the organisation. They work together as a team, in collaboration with the CEO, to ensure that the charity delivers on its charitable aims, and has a clear strategy to deliver the best support for the rare disease patient community.

Trustee meetings are held quarterly, either online or in person in central London or Findacure's Cambridge offices. During these meetings the CEO will provide an update on the organisation's activities and financial position, and the board will discuss the charity's future strategy and goals.

MAIN DUTIES AND RESPONSIBILITIES

- To help the growth and development of Findacure as a leading charity supporting rare disease patient groups.
- Attending quarterly Findacure board meetings.
- Provide strategic advice and guidance to the CEO and Findacure staff.
- To provide oversight on the charity's finances and governance.

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- To attend an annual day-long strategy meeting with the board and employees, and one Findacure event each year.
- To advocate for Findacure and rare disease patient groups, providing useful connections that can help to further the organisations aims.
- To provide ad hoc advice and guidance to Findacure's staff, and (by agreement) Findacure's beneficiaries.

PERSONAL SPECIFICATION

We are looking to appoint at least two new individuals to Findacure's board of trustees. We are in particular looking for individuals with one or more of the following skills:

- **Fundraising and finance** – to help identify new and sustainable funding streams and oversee our financial management. Developing a sustainable long-term model is a major focus for the charity. We are also looking for support with financial oversight, with a new trustee potentially taking on the role of treasurer.
- **Charity management and governance** – to help guide our strategic growth and develop policies for a larger, more professional Findacure. As we grow to become a larger organisation insights into the growth and good governance from a larger organisation would help to ensure the most effective functioning of the organisation.
- **Rare disease experience** – to help with priority setting and bring lived experience to our decision making. Patients and carers have the best understanding of a rare condition. Bringing this perspective to board level will help to ensure we maintain a strong patient focus in all of our work.
- **Online and digital skills** – to help us develop our digital resources and our international reach. Our online resources are a gateway to patient groups worldwide. We want to expand and refine our digital offering and insights into the online world are central to making this a success.



For any appointment we are looking for the following characteristics:

Essential

- Understanding of, and commitment to, the objectives of Findacure.
- Excellent interpersonal and team working skills.
- Comfortable in analysing information, assessing and developing strategy, and providing advice and recommendations.
- A willingness to get involved with the organisation, engage with the rare disease community, and meet the required time commitment of the role.
- Computer literate and comfortable working in an online environment.
- Experience in business, the charitable sector, or living with a rare genetic condition.

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Desirable

-  An understanding of the charitable sector, UK health system, or medical research.
-  Experience in oral presentation and willingness to advocate for Findacure.

Application process

If you are interested in applying for this position please email an up-to-date CV and covering letter to Dr Rick Thompson (rick@findacure.org.uk) by the 29th April 2019, outlining your relevant skills and experience, relating to the listed responsibilities and personal specification.

Shortlisted candidates will be contacted for interviews at our Cambridge Offices in May.