

## M4RD Trustee - Job Description

**Role:** Trustee - unpaid

**Location:** Remote with occasional travel (expenses paid)

**Responsible to:** Chair of Trustees

**Start date:** November/December

**Time Commitment:** The expected time commitment is:

- 4 online Trustees meeting per year;
- 1 face to face strategy meeting or event; and
- Some ad hoc committee work.

However, we are also keen to invite those who are passionate about the charity's work and able to support in other areas.

### Who We Are

M4RD is a UK charity that is advancing rare disease training for medical professionals. The aim of our work is to help reduce diagnostic delay and improve patient experience for those impacted by rare conditions.

We work with an extensive network of patients, carers, advocates and advocacy groups to deliver training to medical schools, foundation schools, royal colleges, hospitals and trusts.

The charity is small and consists of a friendly group of staff and Trustees. The work can be intense but is very rewarding, as the charity responds to the needs of the rare disease political landscape.

### About Rare Disease

An estimated 3.5 million people in the UK live with a rare condition and one of the greatest challenges highlighted by this patient group is lack of medical professional awareness, resulting in delayed diagnosis, greater risk of mental health problems,

progression of the underlying condition, no access to treatment, and even avoidable loss of life.

A rare disease is one that affects fewer than 1 in 2000 in a population, and approximately 7000 rare conditions have been described. Rare diseases have been a health priority in the UK, and across the globe, for many years now, and our power to diagnose rare conditions and our scope for treatment has vastly accelerated in the last twenty years.

However, the accepted approach to medical education on rare disease has changed very little in that time, with virtually no training about how to recognise and manage rare disease - usually only a handful of individual rare diseases are taught in medical education, based on factors such as geographical proximity to a specialist centre, an educator with a special interest, or purely because it's traditional to teach about some conditions in certain specialties. Usually this kind of education has a biomedical focus, rather than the holistic one needed in rare conditions - the majority of which are life-long and cause multi-system involvement.

Medics4RareDiseases is improving the lives of those impacted by rare disease by advocating for mandatory and patient-centred rare disease training for medical students and doctors.

Please take a look at the [M4RD website](#) for more information on our team, and our work.

## **Why Join Us**

At M4RD we are not just talking about change; we are making it happen - as evidenced by the attitude change towards rare disease training in healthcare driven by M4RD for the last five years. By becoming a Trustee, you will play a vital role in shaping the future of healthcare for people with rare conditions. Working with a dedicated team committed to systemic change in medical education, you will bring skills, experience, and knowledge that will support M4RD in achieving their objectives.

## Open Trustee Positions

We are expanding our board and seeking individuals with specific expertise to help us achieve our mission. Our new Trustees will be passionate about supporting the charity to deliver its objectives, and have skills and/or experience in one or more of the following areas:

- Income generation
- Lived experience of a rare condition
- Healthcare education
- Clinical practice
- Lived experience of health and/or social inequality
- Lived experience of societal marginalisation

## Key Responsibilities

- Ensuring the organisation pursues its stated objects (purposes), as defined in its governing document, by supporting the development of - and agreeing - a long-term strategy
- Ensuring that the organisation complies with its CIO constitution, charity law, company law and any other relevant legislation or regulations
- Ensuring that the organisation applies its resources exclusively in pursuance of its charitable objects for the benefit of the public
- Ensuring that the organisation defines its goals and evaluates performance against agreed targets
- Safeguarding the reputation and values of the organisation
- Ensuring the effective and efficient administration of the organisation, including having appropriate policies and procedures in place
- Ensuring the financial stability of the organisation
- Protecting and managing the property of the charity and ensuring the proper investment of the charity's funds
- Following proper and formal arrangements for the appointment, supervision, support, appraisal, and remuneration of the Chief Executive.

In addition to the above statutory duties, each Trustee should use any specific skills, knowledge or experience they have to help the Board of Trustees reach sound decisions. This may involve scrutinising board papers, leading discussions, focusing on key issues, providing advice and guidance on new initiatives, or other issues in which the Trustee has special expertise.

## **Person Specification**

We are looking for people who can demonstrate:

- A commitment to the organisation and its work
- A willingness to devote the necessary time and effort
- Strategic vision
- Good, independent judgement
- An ability to think creatively
- A willingness to speak their mind
- An understanding and acceptance of the financial elements, legal duties, responsibilities, and liabilities of trusteeship
- An ability to work effectively as a member of a team

## **What We Offer**

As a Trustee you will:

- have the opportunity to help M4RD deliver its strategy
- have the chance to be a part of transformational change in medical education, and improve outcomes for people affected by rare conditions
- have access to professional development opportunities, including full Trustee and financial management training
- have the opportunity to work alongside a fun, friendly, motivated, and talented team who work in a progressive way to effect change
- gain experience working with a charity, and opportunities to further connect with stakeholders in the rare disease area
- receive free entry to the M4RD annual symposium and invitations to other events in the field of rare disease

## What you can expect from M4RD

At M4RD we work in partnership, and so we want to support you as you support us. We will provide:

- a full induction to introduce you to the charity, the team, and our strategy and values
- full Trustee training, or a refresher if this has already been completed
- evaluation, and implementation of, any ongoing support you may need in order to fulfil the role
- a designated point of contact for support and guidance
- reimbursement of out-of-pocket expenses, for example when travelling to and from events

## Application Process

- Please apply through Charity Job, attaching your CV and Covering Letter sharing why you'd like to become an M4RD Trustee, and what you can bring to the role.
- We will be accepting applications until 5pm on Wednesday 9th October 2024, and successful applicants will be contacted by the end of October.
- Interviews will be held in early November.

If you have any questions please contact Katie on [katie@m4rd.org](mailto:katie@m4rd.org).

We look forward to hearing from you!