

M4RD Patient Ambassador Job Description



Role: M4RD Patient Ambassador

Responsible to: Medics4RareDiseases CEO and Board of Trustees

Tenure: Two years with recommitment at end of year 1. Maximum term is 2 years with a 12 month period before reapplying to the programme.

Background

M4RD exists to provide education and practical tools targeted at medical professionals, enabling them to reduce the diagnostic odyssey and improve the patient experience.

Thanks to innovation in diagnostics and therapeutics there are increasingly exciting prospects for those living with rare disease. Yet, despite this, patient stories continue to demonstrate a lack of basic understanding by medical professionals of the relevance of rare disease to everyday clinical practice. This perpetuates the existence of the diagnostic odyssey and exacerbates the impact that a rare disease can have on patients and families. M4RD believes that fundamental teaching about rare disease is essential for early recognition of rare disease, coordinated care and early instigation of treatment where available.

We are driving an attitude change towards rare diseases amongst medical students and doctors-in-training in order to improve the patient journey and shorten the diagnostic odyssey. With a packed medical school curriculum and over 7000 rare diseases, it is unfeasible to teach about each disease. However, M4RD has a tried and tested method for raising awareness of the relevance of rare diseases, as a whole, in clinical practice. We are a grassroots movement that is helping grow a future generation of doctors that are rare disease advocates.

Our ambassador programme enables M4RD to work with the wider rare disease community so we can learn from their expertise and experience. Our Patient Ambassadors are really important for making sure that the patient's voice is heard through our work because communicating the lived experience of having a rare disease is fundamental in our message to medical students and doctors in training.

Role description

A patient ambassador is a voluntary representative of M4RD who promotes the work and messages of M4RD within their rare condition advocacy. Suggested activities for the patient ambassador will include:

- Supporting the M4RD team in their aim to raise awareness of rare diseases amongst medical students and doctors in training.
- Providing 1-2 blog posts and/or videos from the patient perspective for M4RD to share on its social media platforms.
- Providing consultation on our activities from your perspective as a person living with a rare condition.
- Promoting the work of M4RD and its message wherever possible.
- Attending events organised by M4RD and their collaborators wherever possible and relevant.
- Representing the charity in a professional manner.

Desirable skills, experiences and qualities

- Experience of living with a rare condition.
- Professional, personable and enthusiastic.
- Confident in public speaking.
- Able to engage on social media platforms e.g. Facebook, Twitter and Instagram.

The benefits to you

- Experience working with a professional organisation.
- A sense of satisfaction and pride for helping to make a valuable difference.
- Positive contribution towards changing/improving medical education or the lives of patients with rare diseases.
- Develop your skills in communication and event management.
- References for future employers.
- Network and meet new people.
- Free entry to the M4RD annual symposium.

What you can expect from M4RD

- An induction session to introduce you to the charity, recognise your skills and identify any ongoing support you may need from us in order to fulfil the role.
- A designated point of contact for support and guidance, when needed.
- Reimbursement of out-of-pocket expenses, for example when travelling to and from events.