

Lay Research Panel Member

Muscular Dystrophy UK is a charity that connects a community of more than 110,000 people living with one of over 60 muscle wasting and weakening conditions, and all the people around them. So everyone can get the healthcare, support and treatments needed to feel good, mentally and physically.

Location: Attends meetings at our London-based office or virtually through Teams or Zoom. Please note that we only accept applications from people resident in the UK.

Department: Research

Frequency:

- The Lay Research Panel meets once a year to assess research applications. This is
 a half- to one-day commitment or sometimes two half days a year. Panel
 members will be expected to read and review several applications ahead of this
 meeting.
- Typically, the Lay Panel meets at one other time of year for a couple of hours to discuss grants that have been funded and areas of strategic importance to MDUK.

Minimum period: 1 year probation, followed by 3 years.

Maximum period: 7 years. If Lay Panel members volunteer for a position as Chair of Vice-Chair, their tenure does not count towards the 7-year total.

How you will make a difference

The Lay Research Panel involves those with a personal or professional connection to neuromuscular disorders (also known as muscle-wasting conditions), in the selection of the best research options to develop treatments and cures for these conditions.

Members of the panel contribute to the evaluation of research funding applications, representing the views of people affected directly or indirectly by a muscle-wasting condition. You understand what is valued by the community of people affected by muscle-wasting condition, so your insights help us to deliver research that will have an impact on lives of those living with the conditions.



What you'll get out of the role:

- The opportunity to input into decisions about the funding of research and to ensure that the views of those affected by muscle-wasting conditions are heard.
- The chance to learn more about current research developments.
- Meet new people and develop teamwork and communication skills.

What you'll be doing:

- Representing the views of people affected directly or indirectly by a muscle-wasting condition when setting the priorities for funding research.
- Reading and assessing plain language applications prepared by researchers. There is no special training required for this, although we often ask people with associations to a particular condition to assess applications with which they might feel a connection.
- Attending meetings of the Lay Research Panel and discussing your views and those of others about the research applications. You will be asked to read some applications in a little more depth and to present those applications to your colleagues on the Lay Panel.
- Contributing towards a score and a recommendation about funding of applications. This will influence the final recommendations made by our scientific committee (the Medical Research Committee).
- Assisting the MDUK Research Team in determining the best ways to communicate research to a lay audience from time to time.

What you'll bring:

- Members of our Lay Research Panel do not necessarily need a background in science or research; you bring your valuable lived experience!
- You will bring an interest in the science of muscle-wasting conditions and an enthusiasm for reading about new scientific and medical advances in the treatment of muscle-wasting conditions.
- You will need the time to carefully read through and evaluate applications in the run up to the Panel meetings.



At MDUK, we're committed to supporting and empowering our volunteers. As such, you can always expect the following from us:

- training and support throughout your time volunteering
- we will share the *Volunteers Handbook* with you, along with regular updates on the charity's work
- opportunities to connect with other MDUK volunteers
- claim back reasonable expenses as agreed with your MDUK contact
- insurance cover, while volunteering, under our public liability insurance
- your personal data will always be held securely in accordance with GDPR and <u>our Privacy Policy</u>
- a formal, written procedure for resolving difficulties; if you have a complaint, it will be dealt with promptly and fairly.

In return, we ask for you:

- to show enthusiasm and commitment to supporting the work of MDUK,
 maintaining and upholding the reputation and good name of the charity
- to listen to, and work co-operatively with MDUK staff and volunteers treating all with courtesy and respect – and adhering to the Volunteer Code of Conduct
- to take reasonable care of your own health and safety and that of others around you
- to support the charity's equal opportunities and diversity policy
- to provide us with feedback on your volunteering experience and let us know if you can no longer volunteer with us

Other requirements

GDPR training: Required

Confidentiality agreement: Required

Conflict of interest declaration: Required

Travel: Can attend meetings at MDUK

London office or virtually via Zoom / Teams

Access to internet: Required – Needs own equipment



Application process

- We usually request applications from late September/early October with an application deadline of late October/early November.
- Shortlisting will be done by the Lay Research Panel and usually takes place in mid-late November.
- Interviews will be in late November-early December. Interviews will be held via Teams/Zoom. The panel will consist of existing members of the Lay Research Panel and members of the Muscular Dystrophy UK Research Team.
- You will be notified of the outcome of your application by about mid-December.