**Job Description and Person Specification: Research Officer**

**Job Title:** Research Officer (homeworking)

**Job Type:** 12-month contract (it is hoped the project will be funded for an additional year at the conclusion of this contract)

**Responsible to:** Chief Executive Officer

**Working hours:** Part Time – 24 hours per week with evening and weekend work as required. Job shares may be available where matching candidates can be identified.

**Salary:** £25,591-£28,672 p.a. (pro-rata), dependent on experience.
This will be determined by amount of relevant previous work experience and complexity of research projects previously delivered.

**Base:** Homeworking

**Deadline:** Application deadline is Friday 26th February at 12pm. Interviews will be conducted on Tuesday 2nd March between 12pm-4pm.

**Overview:**

Pathfinders Neuromuscular Alliance is a user-led charity which promotes choice, control and quality of life for teenagers and adults with neuromuscular conditions.

Pathfinders aims to enable teenagers and adults with neuromuscular conditions to access the support they need to maintain good health, become independent, access social and work opportunities and contribute to their communities. We want to ensure standards of care and access to services and information is consistent across the country. We want to develop the skills and confidence of young people with neuromuscular conditions and empower them to take charge of their own health and to build a stronger community to get better services and support.

We are currently recruiting a Research Officer to oversee a qualitative research project exploring transition outcomes for young people living with Duchenne Muscular Dystrophy across the UK and 2 European countries. The Research Officer will coordinate the project, facilitating research design, fieldwork and analysis and management of a team of peer co-researchers to support the project. This research project is being managed exclusively by Pathfinders, with funding from PTC Pharmaceuticals. The Research Officer will be managed by the CEO who will play a supporting role in project management and linking resources and contact into the project.

Please note all aspects of this role will be carried out remotely, and the successful candidate will work from home. There may be opportunities for in-person dissemination of results if the project is extended in 2022, but only if this is deemed to be Covid-safe to individuals who are currently shielding.

We are particularly interested in employing people with lived experience of a neuromuscular condition, particularly adults with DMD but also people with other conditions, carers, siblings, parents etc. However due to the urgent nature of the work, the role is open to all, including those without lived experience.

It is essential that all of the people that we employ embody the values of Pathfinders, enabling and encouraging independence, being led by the people we support, rooted in the social model of disability and valuing the importance of sharing lived experience.

**Key Objectives of this role:**

* Recruiting and managing peer co-researchers with DMD across three countries, and facilitating their involvement in research design, fieldwork and analysis
* Overseeing and directly conducting literature reviews, research design, fieldwork, and thematic analysis for the project, guided at each stage by peer co-researchers
* Convening a steering group of academics, co-researchers and adults with DMD to guide the project
* Building relationships with DMD organisations as research partners
* Promoting and recruiting research participants for the project
* Publicising and reporting to the community regarding progress on the project
* Reporting on and disseminating project findings
* Identifying and pursuing wider outcomes to support the adult DMD community

**The Research Project**

An international collaboration between DMD patient groups led by Pathfinders Neuromuscular Alliance, to gather data from teens and young adults with Duchenne Muscular Dystrophy regarding their experiences of transition to adulthood and the impact this has on quality of life.

The study will be informed by previous work on transition such as (Carpenter and Abbott 2010), as well as previous work using disabled peer co-researchers (Abbott and Hastie 2012, Liddiard et al. 2018) in which Pathfinders has been involved.

The research materials, developed by adults with DMD, will be translated, localised and used by co-researchers in 2 other countries, building on the experience of the UK.

This will be the first study designed and delivered by adults with DMD themselves. This peer-led research will gather valuable data for planning future activities to improve transition outcomes, and will also explore the value and impact of peer-led research as a means of gathering rich, contextualised data. It will create a model for future peer-led research that can be applied to different patient communities across the world. It will also empower the DMD community by creating work opportunities and facilitating skills building of young adults with DMD, preparing them for future employment.

**Goals**

· To inform a new understanding of natural history and disease progression for a new population of DMD patients who have had access to increased corticosteroid use and other clinical trials.

· To inform how the current clinical and drug development landscape for DMD has impacted on transition outcomes for young adults with DMD.

· To understand and document issues impacting on quality-of-life of young adults with DMD during the transition phase, providing a means to contextualise data in quantitative quality-of-life measures.

· To highlight the value of community peer-led research (i.e. patients talking to patients) in yielding relevant data and, it is hoped, generating a transformative understanding of transition pathways for DMD patients.

· To create a setting in which teens, young adults and parents can share experiences and access peer support from adults with DMD who have undergone similar experiences.

· To provide experience for adults with DMD as peer co-researchers, developing skills in interviewing, data processing and analysis.

**Person specification**

In your application you will need to explain how you meet the following requirements:

You must either have a Bachelor's degree with a 2:1 or above or equivalent in a course with a strong focus on independent research and specific training in research skills OR a Masters degree with specific training in research skills.

You will need to demonstrate experience of carrying out a research project, including research design, data collection, qualitative interviewing and analysis. You will need to explain the details of this project and the tasks you were required to perform, as well as the outcomes you delivered.

You will have a good understanding of the essential characteristics of the research process, including ethics, relevance, impartiality, critical thinking and confidentiality.

You will need experience of working to deadlines, setting and meeting objectives and targets, and reporting on your work.

You should have experience of working in an environment where you have had to demonstrate integrity, professionalism and adherence to policies and procedures to keep people safe. This does not need to have been a paid role.

You should have experience of working with others and coordinating your work with colleagues or other team members.

You should have experience of writing blogs or other materials for both lay and professional audiences.

You will need to have excellent communication skills being able to build good relationships with others, particularly with service users who may be lacking in confidence and reluctant to engage. You should be able to put people at ease while talking to them, and be able to engage with them about their interests. You should be skilled in building friendly and supportive relationships while maintaining professionalism. You will need to demonstrate empathy and understanding to the adults and families you will support.

You will need to be able to communicate with professionals and academics effectively to communicate your research and to incorporate feedback.

You will need to be able to demonstrate effective public speaking skills when describing and disseminating the results of your work.

You will need to be able to research and identify resources and solutions as needed. This includes identifying and liaising with other organisations, both patient organisations and providers of research, transcription and translation services.

You will need to demonstrate excellent proficiency with IT and social media, particularly the use of apps such as Zoom or equivalent, WhatsApp, Facebook, Twitter and Instagram. You will need to be familiar with conducting online meetings.

**Application process**

Please contact Pathfinders for an application form - at info@pathfindersalliance.org.uk - or download from our website

