JOB DESCRIPTION

Job Title:	**Research Analyst**
Department:	**Support Services**
Reporting to (Job Title):	**Chief Executive Officer**
Direct reports:	**None**
Date of issue:	**8th September 2022**

OVERALL PURPOSE OF ROLE

MAIN ACTIVITIES AND RESPONSIBILITIES

Established in 2004, Alex TLC offers a recognised and trusted package of practical and emotional support for those affected by leukodystrophy, using the lived experience of staff and our excellent relationships with condition specialists. As the charity has grown, there is an increased demand for specific expertise with which to engage more effectively with researchers, respond to relevant health consultations and promote access to new treatments and early diagnosis.

This role is the first of its kind within Alex TLC and comes alongside the roll out of a new NHS England Inherited White Matter Disorder (or leukodystrophy) Patient Service and Registry. Alex TLC have been heavily involved as the lead patient voice representative for the Development Committees, and the Research Analyst will work closely with the team involved.

As part of our strategic growth, more dedicated involvement in research is a priority for the community we serve. This role will enable us to deliver more research related work including more effective responses to health-related consultations, targeted engagement with research organisations and scientists, and helping our community understand the pathways to, and impact of, research for their individual conditions, through regular research updates.

Monitoring and evaluation are key aspects of our work, and the Research Analyst will analyse Alex TLC community feedback data as part of their input into a variety of Alex TLC projects, including community resource and activity development, as well as deliver the organisation's impact reporting duties.

The Research Analyst will work under the supervision of the Chief Executive Officer and alongside the Support Services Manager, reporting monthly against set targets to the Chief Executive Officer as part of the Senior Management Team.

Relationship building is a key aspect of the role, and the Research Analyst will work to develop and maintain key collaborations with relevant research and health stakeholders.

Responsibilities include but are not limited to:

- Analysis of internal and external data resources (published evidence e.g. PubMed, Alex TLC database and community feedback, NHSE IWMD Patient Registry, peer organisation data resources) and production of relevant documents, including:

- - Alex TLC Impact Reports
    - Project-related reports and input (external and internal)
    - Health consultation responses (e.g., NICE, NHS, National Screening Committee)
- Horizon scanning for new research related initiatives and opportunities
- Curation of Alex TLC research stakeholder network
- Collation of monthly Alex TLC community Research Updates, containing information about recent research and clinical trials, ensuring language used is accessible and sensitive
- Engagement and collaboration with the new NHSE Inherited White Matter Disorder Service and Registry
- Full comprehension of Alex TLC policies, systems, and processes
- Raising awareness through conference attendance and presenting opportunities

OTHER FEATURES OF JOB (TRAVEL, HOURS OF WORK, WORKING CONDITIONS ETC)

The role is full time, 40 hours per week, and includes a daily unpaid break of one hour.

Any additional travel expenses necessary to the role are remunerated according to Alex TLC's Expenses Policy and individual employment contracts.

LOCATION

The role is flexible and can be home based or located at the Alex TLC Head Office, 45 Peckham High Street, London SE15 5EB.

PERSON SPECIFICATION

EDUCATION, QUALIFICATIONS AND TRAINING
ESSENTIAL:

- PhD or relevant experience

DESIRABLE:

- Academic focus on genetics, neurological and/or rare disease

EXPERIENCE
ESSENTIAL:

- Experience in using evidence to promote improvements in patient outcomes
- Experience of working within a research and/or data analysis setting
- Experience of developing and maintaining stakeholder relationships

DESIRABLE:

- Understanding of the work of Alex TLC, leukodystrophy, rare disease challenges and opportunities
- Lived or work experience involving leukodystrophy or a similar rare disease
- Experience of working within an advisory service environment
- Knowledge of national health organisation infrastructures

WORK BASED & BEHAVIOURAL COMPETENCIES
ESSENTIAL:

- Commitment to working creatively within a team to reach targets

- Excellent co-ordination and organisational skills, including ability to prioritise and plan own workload, manage multiple tasks and work to tight deadlines
- Ability to respond to client or manager feedback and improve services
- An open minded and challenging approach to work
- Excellent analytical skills
- Excellent communication skills
- Emotional intelligence (when relaying sensitive research information to beneficiaries)
- Excellent IT skills: MS Office, database systems
- Experience in the production of written reports or similar.

DESIRABLE:

- Knowledge of e-Tapestry database
- Working for a small patient support organisation