

Post: Information & Research Hub Manager

Responsible to: Chief Executive

Member of: Information Team

Significant relationships with: Support Team
Communications Team
Office Manager

Based at: CLDF Office, Birmingham

Scope of role: National

Requirements: Willing to undergo training
Willing to undergo safeguarding children training
Willing to travel nationally and undertake overnight stays and weekend work
Clear Enhanced Disclosure from the Criminal Records Bureau

Principal Purpose and Approach

The Information and Research Hub Manager will be responsible for setting up a research hub to broker patient and family perspectives into the effective design of research into childhood liver diseases. The post will also be responsible for our biennial national conference and responding to medical and support based enquiries, managing the review and development of patient and parent resources, including literature and keeping CLDF informed of relevant research in the field and its dissemination to supporters.

The post holder will be responsible for maintaining and developing CLDF's profile and relationship with healthcare professionals and professional bodies. The Information and Research Hub Manager will also take responsibility for health information campaigns such as Yellow Alert and support CLDF's work to be the voice of paediatric liver disease in relation to policy work. The role will provide a front face of CLDF and thus will require a high standard of customer care.

Duties

Resource & Information Provision and Management

1. To respond to medical and support based enquiries and provide data on needs and key issues.
2. To manage the review and update of patient and parent resources, in line with Information Standard protocols.
3. To manage the development of new patient and parent resources to include apps and child centred resources.
4. To work with the Digital Communications & Web Design Officer in the provision of patient and parent information via CLDF's websites and social media platforms.

5. To organise, manage and coordinate CLDF's biennial conference weekend for families, liaising with professionals and venues and developing programmes.
6. To manage CLDF's professional approach to information provision and education, adopting best practice.
7. To manage CLDF information campaigns e.g. Yellow Alert and support the communications team in their work with awareness programmes.
8. To contribute articles for CLDF publications and on-line sources, as required.
9. To liaise with the Office Manager (who provides administrative support to the research portfolio management) and take the outcomes of CLDF's research programme and work with the communications team for their dissemination.
10. To keep up to date with research findings in the field and disseminate information to supporters, ensuring it is readable and appropriate.
11. To maximise the use of resources and direct, manage and supervise volunteers to ensure the objectives of the role are met.

Research Hub Management

1. To manage the Research Hub project. Recruiting and training a panel of parents and young people affected by childhood liver disease who can be called upon to provide input on research design to external researchers.
2. To promote the research hub to researchers in the field, act as brokerage manager and support PPI focus sessions.
3. To help develop and manage a research hub area of the website for dissemination of information to young people, families and professionals interested in childhood liver disease and related research.

Awareness & Promotion

1. To manage CLDF presence at relevant professional conferences and meetings.
2. To work with the Support and Communications teams to create awareness of paediatric liver disease and the work of Children's Liver Disease Foundation.
3. To work with the CEO to voice the needs of parents / carers, children, adolescents and adults diagnosed in childhood and provide information, as required. To be the main contact for NICE and to actively manage systems for eliciting user feedback on a wide range of policy issues which affect our service users.

Liaison & Team Working

1. To liaise and develop meaningful relationships with medical and allied healthcare professionals.

2. To liaise and develop meaningful relationships with other relevant organisations and professional bodies.
3. To work with the Communications team to provide relevant advice, support, information, materials and articles for professional e-news and other supporter based communications.
4. To liaise with research teams working on CLDF funded projects, as required.
5. To work with the Families and Young people's teams to develop appropriate, innovative and creative resources and projects to meet the needs of the groups.
6. To take part in off site families and young people's projects and one day themed projects as required.
7. To take part in multi-disciplinary projects, as required.
8. To provide reports and data, as required.

Notes

1. At all times the post holder will need to be mindful of the delicate working relationship and interface with families, supporters, medical professionals, specialist liver units and hospitals units and advisers.
2. CLDF operates with a small work force in which every member of the team is expected to work flexibly in order to contribute to the overall objectives and mission of the charity thus staff are expected to provide cover for colleagues as directed by line management.
3. The service will be offered and carried out in a manner regardless of ethnicity, gender, social class, ability, religious affiliation and sexual orientation of the service users or other CLDF employees.
4. CLDF reserves the right to alter the content of this job description, after consultation, to reflect changes to the job or services provided, without altering the general character or level of responsibility.
5. The post holder will be expected to ensure conformance with CLDF's values and brand guidelines at all times.
6. The post holder will be expected to ensure that all educational and research activities comply with current and relevant legislation and follow the best practice principles.
7. The post holder will be expected to keep up to date with external developments within the sector, identifying innovative opportunities and advise on new and appropriate approaches for the charity.
8. Training, mentoring and coaching will be encouraged as well as membership of appropriate professional bodies.
9. This is a Display Screen Equipment (DSE) user regulated post.

Performance Management

Performance will be assessed by means of a formal monthly progress review with the Chief Executive, annual appraisal process as well as review of performance in group projects and other CLDF activities. Specific areas of measurement will be as follows:-

1. The quality, timeliness and effectiveness of work undertaken and its impact upon the CLDF team.
2. The achievement of objectives and targets and the contribution to the overall objectives of CLDF.
3. The general quality, effectiveness, efficiency and good order of the provision of information and research services.
4. The degree of initiative, general approach and attitude towards the role.
5. The ability to work within a team and the development of effective and constructive relationships with the team.
6. The development of effective and constructive relationships with other members of the CLDF team, volunteers who interface with the Foundation.
7. The strength, maintenance and development of effective relationships with families, external stakeholders and supporters.
8. The added value generated for CLDF through the performance and delivery of the role.
9. The ability to relate to CLDF's values and mission.

Person Specification

Attributes	Essential	Desirable	Measured by
Knowledge / Qualifications	Educated to degree standard		Application and certificates
		Understanding of how illness affects the family and the need to communicate effectively.	Application & Interview
	Understanding of the essential components of delivering public information programmes through a range of channels including digital media		Application & Interview
	Thorough understanding of the delivery of healthcare in the NHS		Application & Interview
	Experience of communicating research findings		Application & Interview

Attributes	Essential	Desirable	Measured by
	Experience of researching information and translating for lay audience use	Understanding of the components of safeguarding children and vulnerable adults	Application and Interview
Experience	At least three years' experience in delivering information services	Experience of delivering services via remote means – telephone, email, forums, social networking	Application and Interview
	Successful track record of implementing project work and the achievement of targets	Demonstrate experience in building and maintaining relationships	Application and Interview
	Experience of working as part of a multi-disciplinary team	Experience of managing volunteers	Application, Interview and Exercise
	Demonstrate knowledge of big picture in the provision of healthcare and support information and the NHS		Application, Interview and Exercise
Skills and Abilities	Numerate & IT literate		Application, Interview and Exercise
	Ability to write accurate records and reports		Interview
	Ability to manage time effectively and prioritise work		Interview and Exercise
	Ability to generate ideas and solutions		Interview and Exercise
	Ability to multitask and achieve deadlines and objectives		Interview
	Excellent listening & communication skills – written & oral with a range of people		Interview and Exercise
	Ability to provide advice, information and support in a way which empowers		Interview
	Ability to assess and summarise accurately and effectively		Interview
	Ability to maintain positive relationships with service users and other stakeholders		Interview
	Ability to work accountably as part of a small team		Interview
	Ability to work under pressure to meet tight deadlines		Interview
	Ability to work independently and with initiative		Interview
	Highly organised and methodical		Interview
	Commitment to producing accurate and quality work		Interview
Personal Attributes and	Engaging, empathetic, enthusiastic and sociable		Interview

Attributes	Essential	Desirable	Measured by
Qualities	Adaptable and able to view change positively		Interview
	Driven, energetic, confident and self motivated		Interview
	Team player		Interview
	Friendly, open manner and open minded		Interview
	Prepared to work in a flexible way		Interview
	Unafraid to take on new situations and challenges		Interview
	Tactful & diplomatic		Interview
	Committed to innovative service development		Interview
	Committed to the cause overall and able to see beyond the role and department		Interview
Circumstances	Ability to work out of office hours		Interview and application
	Able to travel throughout the UK and work irregular hours, when necessary		Interview
	Valid UK driving licence		Copy to be provided
	Able (and unafraid) to travel to and attend events to represent CLDF		Interview
	Able to undertake an overnight stay when required		Interview

Competency Profile

Refer to definitions

	Competent	Skilled	Advanced	Expert
Personal effectiveness			X	
Planning and decision making			X	
Communications and Influencing		X		
Building and maintaining relationships		X		
Developing yourself and others	X			
Innovation			X	
Specialist Knowledge			X	

Benefits

- £27,000 - £30,000 dependent upon experience.
- 20 days annual leave increasing by 1 day per annum to a maximum of 25 days, plus bank holidays and discretionary office Christmas closure days.
- Death in service benefit – twice annual salary.

- From 1st January 2017 CLDF operates an auto enrolment pension scheme for all eligible job holders, as is legally required. The initial contributions are 2% for both the employer and employee, rising on a phased basis determined by the government. The scheme is with Royal London.
- Staff Committee to organise social and other activities.

Notes:

CLDF reserves the right to alter the content of this job description, after consultation to reflect changes to the job or services provided, without altering the general character or level of responsibility.

The above list of responsibilities is not exhaustive and may change to meet the needs of the organisation. The post holder may also be required to carry out such other duties as may be required from time to time which are broadly consistent with the status of the post within the organisation.

January 2018