

Research Hub Member Role Description

Volunteer role title:	Research Hub Network Member
Department:	Research Hub
Location:	Any (occasional meetings in a central location)
Main contact:	Harpreet Brrang (Information and Research Hub Manager) research-hub@childliverdisease.org

Background and Aims:

CLDF are recruiting those who have experience of childhood liver disease either as a patient or parent/carer to be part of our newly developed research hub.

The CLDF Research Hub aims to ensure that the research we fund meets the priorities of patients and carers and that they are at the heart of research projects.

This is your chance to shape research and change the lives of those affected by childhood liver disease.

What the role involves	
	<ul style="list-style-type: none"> To support researchers to review methodology and design, reshape and clarify research questions To help researchers frame research priorities Take part in semi-structured interviews and/or questionnaires Review lay documents Participate, and encourage others to participate, in the final study Promote ongoing projects and help share the results Promote the hub in your areas/networks To support to campaign for implementation of research findings where appropriate
Time commitment	<ul style="list-style-type: none"> Ad hoc – as and when available
Method of communication	<ul style="list-style-type: none"> Email Skype Phone Social Media Post One off meetings or focus groups
What we can offer you	<ul style="list-style-type: none"> Telephone call and/or face-to-face induction (as appropriate) Briefing documents and/or pre-meeting notes provided Project updates Quarterly research hub newsletters Training opportunities where appropriate Ongoing contact with Information & Research Hub Manager
What we are looking for:	<ul style="list-style-type: none"> Experience of living with childhood liver disease as a patient, family member or friend Aged 16 and over Must be able to prepare for and attend meetings if they have agreed to the opportunity and this was stated as essential

	<ul style="list-style-type: none"> • Must maintain confidentiality in relation to discussions that take place in focus groups and meetings as well as personal experiences shared • Must be confident to question researchers when necessary in a polite and constructive manner • Be able to use personal experiences of childhood liver disease to support researchers with their study whilst respecting differing views from other members • Members must be reliable and trustworthy • Members must declare any conflicts of interest
Location	<p>Many involvement opportunities may not require any travel and will require communication through email and online platforms only.</p> <p>Face-to-face meetings may be required on occasion. We will endeavour to ensure this is in a central location and/or the CLDF office in Birmingham City Centre, however, this will be dependent on the research study.</p>
Duration of the role	Ongoing
Payment and expenses	Standard class travel, mileage and ad hoc expenses will be reimbursed where appropriate. Where meetings run over lunchtime, food and refreshments will be provided. A CLDF expenses form must be completed to claim this.
How to apply	Please register your interest by completing the short contact form available at: https://childliverdisease.org/patient-and-public-involvement-in-research/

Once we receive your application:

- We aim to process all applications as quickly as possible
- You will receive an acknowledgement of your application and an informal discussion will be arranged to discuss further. An induction pack will be provided and training/networking days where possible.

Any questions?

- If you have any queries about this role or the CLDF Research Hub please contact:
Harpreet Brrang (Information and Research Hub Manager)
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0121 212 3839
research-hub@childliverdisease.org
- <https://childliverdisease.org/research/research-hub/>

Thank you for your interest in this role.