



## **We are seeking an Engagement Volunteer**

We are a small national charity supporting children and adults with a rare genetic disease: can you help us run events and raise funds?

### **The Role**

We are looking for a volunteer to help us engage our community through organising events and fundraising activities.

We are a small charity set up as a charitable trust in 2019 with modest funds. Our activities were disrupted by the pandemic, but we have now held two successful family days, providing support and information for our patient community. We are now registered as a Charitable Incorporated Organisation (CIO) and are looking to strengthen our team of volunteers.

XLH and related disorders are rare and so building awareness and engagement requires a tailored approach, working through our community of those who have the condition and their families. We have a website, Facebook page and newsletter and try to run at least one networking event a year. We are looking for a volunteer with an interest in getting involved with the Charity in the longer term, who

- Has the ability to work as a team member and contribute flexibly
- Has some skills in event management and communication
- Is motivated to contribute to better health outcomes for people from all walks of life
- Understands the resource constraints of a small charity

### **Skills**

- Digital communication skills using standard platforms required
- Any suitable fundraising or marketing experience would be advantageous

We run informal team meetings remotely so we can consider candidates from across the United Kingdom (UK). There are no set work hours – meetings will be set at a time which is convenient for most. Time commitment depends on volunteer availability, ideally 1-2 days a month, with flexibility to travel to occasional events.

### **Making a difference**

Your help will make a big difference to our charity – by running events we will be able to engage our community and become a stronger patient-led charity. We currently have life-changing treatments undergoing review for NHS funding; keeping our network informed is vital. Fundraising for XLH UK will enable us to continue to support children and adults across UK to get their best care.

### **What's in it for me?**

You would be part of a small, friendly team with the opportunity to make a real difference in challenging times.

August 2023

Registered Charity (England and Wales) 1196811