



We are seeking an Administration Volunteer

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

The Role

We are looking for a volunteer to help us with correspondence and administration.

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 restarted activities providing support and information for our patient community. We are registered as a Charitable Incorporated Organisation (CIO) and are looking to strengthen our team of volunteers.

XLH and related disorders are rare and so communication is important to our community of those who have the condition and their families. We have a website, Facebook group and newsletter and try to run at least one networking event a year. The trustees organise research, speak at conferences and manage marketing, finance, governance and events alongside their paid employment.

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 administration and is comfortable with digital communication
- Is motivated to contribute to better health outcomes for people from all walks of life
- Understands the resource constraints of a small charity

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, a few hours twice a week would be ideal.

Making a difference

Your help will make a big difference to our charity – by supporting us with the administration of running a Charity you will free up time for the trustees to work on other priorities. We currently have life-changing treatments undergoing review for NHS funding; contributing to this process and keeping our network informed are vital activities. With financial security we can continue to support children and adults across UK who have XLH to get the support they need to thrive.

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.