

Could you support us as a trustee?

We are the only registered charity supporting children and adults in UK with a rare genetic disease: can you help us to help them?

The Role

We are looking for trustees to contribute to a Board of dedicated volunteers who both lead and run the charity. X-linked hypophosphataemia (XLH) is a lifelong, multi-symptom condition that affects both children and adults in a variety of ways. We are keen to have support from individuals with any of the following expertise: Finance, Healthcare or Communications.

We are a small charity that was set up as a charitable trust in 2017 with modest funds. Since then we have been building a patient community, catalysing international exchange and doing research to inform a series of Health Technology Assessments. Our work has directly contributed to many more patients accessing better care, but there is still more to do. We are now registered as a Charitable Incorporated Organisation (CIO) and are looking to strengthen our friendly Board.

We hold Board meetings virtually once a month, so we can consider candidates from across the United Kingdom (UK). We aim to meet face to face at least once a year at our annual Family Day. The role is voluntary, but we cover any out of pocket expenses. Time commitment depends on volunteer availability, ideally 1-2 days a month.

The ideal trustee

- Has the ability to work as a team member and contribute flexibly
- Has some experience of contributing to an organisation at a senior level
- Is motivated to contribute to better health outcomes for people from all walks of life
- Understands the resource constraints of a small charity

Making a difference

With your help we will be able to fulfil our responsibilities according to our charitable objects. As a trustee you would help us define a sustainable strategy, providing information, advocacy and support for adults and children across UK who have XLH or related disorders.

What's in it for me?

You will join a diverse community with experience of living with a rare condition, becoming part of a small, friendly team with the opportunity to make a real difference in challenging times.

For further information, please check out our website at <https://xlhuk.org/>

If you are interested in having a confidential discussion about the role, please contact sarah@xlhuk.org