

Could you support us as a trustee?

We are a small national charity supporting children and adults with a rare genetic disease. As current Board terms are nearing completion, we are looking for new trustees.

The Role

The charity was set up in 2019 to provide support and information for individuals across the UK who have X-linked hypophosphataemia (XLH). We serve a vibrant community, have a strong reputation and a track record of successful fundraising. This is an exciting time to join, as we have just hired a part-time charity manager and are transitioning to a Board with less operational responsibilities.

We are particularly looking for trustees with experience and connections in the medical and health sector; to contribute to XLH UK strategy and sustainability, and to help us to improve access to better care and treatments.

The ideal trustee will

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

We are set up digitally to ensure efficient management and communications. We hold Board meetings virtually once every two months, so we can consider candidates from across the United Kingdom (UK), aiming to meet face to face at least once a year. The role is voluntary, but we cover any out of pocket expenses. Time commitment depends on your availability, ideally 1-2 days a month.

Making a difference

With your help, we will fulfil our responsibilities as a valuable resource for our patient community. As a trustee you will help us to sustainably deliver our mission; to provide information, advocacy and support for adults and children across UK who have XLH or related disorders.

For further information about the charity, 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

We hope that you will feel part of a small, friendly team and that you will see the impact you have, helping us to thrive as a strong patient-led charity.

We are an equal opportunities charity. No applicant will be treated less favourably on the grounds of their sex, marital status, race, nationality or ethnic origin, disability, sexual orientation, gender identity, age or religion.