Name: Sally Hatton

Joined: October 2019 (Age 28)

Country: United Kingdom

Name of the Organization:

XLH UK & The International XLH Alliance

About my Organization:

- We are working towards a brighter future for everyone with XLH and related disorders by funding cutting-edge research, driving up standards of care and supporting people with the condition and their loved ones every step of the way.

How to contact me:

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About me:

Hi. I'm Sally and I'm from Manchester in the UK - it's famous for Football (Manchester United for me), music - and rain! I live with a rare bone condition called XLH, or X-Linked Hypophosphatemia, which causes bone and muscle pain and weakness, and can mean a person looks and walks differently. The condition is inherited but you can also develop it spontaneously which is what happened to me so I have no one in my family with the condition. In fact, XLH is so rare that I was 25 before I ever met or spoke to anyone else with the same condition as me. Growing up I had struggled with dealing with the mental and physical impact of having a condition and being 'different', and had some difficult operations, including learning to walk again. Because of that, I can truly appreciate the difference it makes to be able to share your experiences with a patient community. I volunteered with XLH UK as soon as I heard about them and we've also been working with other XLH organisations across Europe and the world in the International XLH Alliance to make a difference to XLH Patients everywhere, and I also work with an umbrella patient organisation for inherited metabolic disorders looking at the needs of young people. I also attended EPF Summer Training for Young Patient Advocates in 2019 and it was a life changing experience. In my spare time, I love keeping busy seeing friends and travelling when I can, and I'm also a bit of a nerd - anything science fiction or Marvel and you can count me in!