

Shine a Light on XLH

Anu & Tia's story

Anu and her daughter Tia both live in Vantaa, Finland. Anu was diagnosed with X-linked Hypophosphataemia (XLH) at the age of 24, and Tia was diagnosed at the age of six months – an early detection as a result of Anu's knowledge of the disease. There is a history of XLH in the family, with Anu's mother also living with the disease, though this was detected as a result of Anu's diagnosis.

Anu describes the diagnosis of X-linked Hypophosphataemia (XLH) as having been "complicated". Although it was clear to doctors that she was experiencing difficulties from a very young age, confusion over the cause meant that she received ineffective treatments which did not help.

Anu also struggled with the cruelty of others, who would be unkind to her due to her short stature and difficulties walking. She had good friends who supported her during childhood, but always felt like she was an outsider and the only person in the world living with her problems.

Anu received her XLH diagnosis at the age of 24, an event which gave her a sense of relief in being able to be able to put a name and a cause to the symptoms she was experiencing. To help with her mobility and strength, Anu has undergone several surgeries, including three extensive bone correction surgeries and replacements for both of her hips; however, these did

not alleviate the pain caused by XLH.

Anu is most affected by her leg pain, which has resulted in the need for home adjustments such as handrails.

The most frustrating consequence of her XLH pain is the impact it has on her social life. Anu struggles to stand in one place for long periods of time due to her pain, forcing her to avoid attending social events with her friends and colleagues, or going to places where she knows she will have to queue. She also experiences hearing difficulties, which she finds particularly frustrating in her job as an accountant, as well as a range of dental issues.

"There was no awareness of XLH when I was younger. It was really horrible, as I thought I was the only person on the planet with this thing and that nobody knew what it was." - Anu

In the last ten years, Anu's attitude towards her disease has changed in a positive way, and she now feels more confident to ask for help from others where needed. Looking forward, she would like to see improvements in care for people living with XLH, with effective dental care and physiotherapy being particularly important to her.





“The happiest day of my life was when we found out about the XLH Alliance, because it really opened us up to the world and made us see that there were a lot of people with XLH out there.” - Anu

Tia’s experience of living with XLH has been different to her mother Anu’s as a result of receiving a diagnosis at a very young age. She has also benefited from the support of her mother and her grandmother and their understanding of what it is like to live with XLH.

During her childhood, Tia had several surgeries, which left her with a very slow and painful healing process to contend with. Tia found her teenage years to be a struggle, as she felt different from her peers and found it hard to fit in, wishing she could “just be normal”. She still experiences frequent and debilitating pain.

Tia, who works as a claims advisor for an insurance company, believes that people don’t understand the level of pain she experiences because people with XLH can look ‘normal’. She also struggles with the misconception that when she says she can’t do something, it’s not because she doesn’t want to, but because she is in pain, or because she knows she could be left in pain for several days afterwards as a result.

In the future, Tia would love to be in a position where her XLH doesn’t hold her back. She loves to surf, and dreams of the day when she will be able to surf without suffering for days after.

“Learning to accept that XLH is a part of me, but not all I am was a turning point for me. It made me realise that I don’t have to be embarrassed anymore.” - Tia



“I want to raise awareness that XLH is always there and it affects us every day in everything we do, but it doesn't make our lives bad, it just makes them different.”
- Tia

However, Anu and Tia want people to know that their enjoyment of life is not hindered by XLH. Anu is pleased that awareness of XLH has improved over the years, and Tia is grateful to have had access to support from a young age. Tia also has made meaningful friendships with others living with XLH, and growing up had the opportunity to participate in activities such as horse riding, yoga and dancing that were not possible for Anu when she was younger.

Anu and Tia both hope that understanding of XLH will improve in the healthcare professional community, so they no longer feel the need to be the experts on their own disease. Tia also wants to be able to start a family, safe in the knowledge that if her children do have XLH, they will receive the care and support they need.

About the makeup

The blue frame on Anu's chest represents perception looking through a window. Anu discusses her happiness that Tia has had access to support which she did not receive when she was younger. The hand on heart refers to her new willingness to ask for a helping hand and how she's grateful for the continued efforts to improve support for people living with XLH. Finally, the beam of light racing up through the neck and face showcases Anu walking forward, as she hopes to still be able to walk well in 20 years' time.”

“Tia talked about her dream to surf, riding the waves to fulfil a feeling of freedom from the daily pain and restriction XLH can bring to her. She is young and positive about her future living with XLH and optimistic about the continued support she wants to see for people living with XLH. The light beams coming from the waves connect from the chest up towards her face - the colour contrast of pink and orange represents healing and perseverance.”

- James Mac Inerney, Makeup Artist

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