

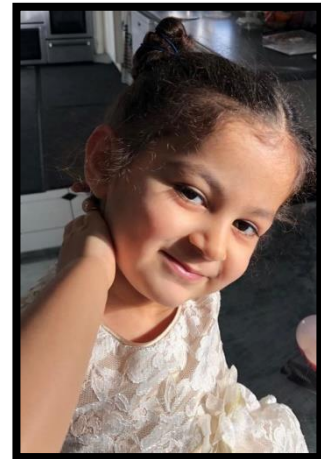
Jeevna's story September 2022

Name of service: Children's Expert Team

Main purpose of service: Our team includes; Nurses, Physiotherapists, Occupational Therapists, Speech and Language Therapists, support staff and a Play Practitioner.

We specialise in supporting families and assessing and treating children so they can be as independent as possible.

About the person: Jeevna is 3 years old. She was born with a rare condition called Tibial Hemimelia, whereby all or part of the tibia (shin bone) is missing and the foot, sometimes referred to as 'club foot', is turned in. To find out more; [Tibial Hemimelia Factsheet v3 \(stepsworldwide.org\)](https://www.stepsworldwide.org)



Determined: Jeevna's Dad Surjeet recalls when she was born. **"Nothing had been picked up on in any of the scans, so we weren't expecting anything different. They wrapped her up in blankets and handed her to me. I put my hand into her blankets to feel her feet – to touch and play with her feet I suppose– and straight away I could tell something was different."** Jeevna was referred to Sheffield Children's Hospital. **"We got really lucky there! Mr Fernandes is a one of the best in the world with Tibial Hemimelia. We were told Jeevna's left foot was 'non- functional'. It didn't have enough bones in it and that it was best to have it amputated and for her to have a prosthesis."** It was suggested that Jeevna's right foot needed surgery too, but would not be amputated. A second opinion from Great Ormand Street Hospital confirmed that this plan was the best option for Jeevna. Surjeet explains that the operation to amputate was delayed due to the pandemic, and meanwhile, as Jeevna developed and grew, nothing would stop her! She was able to move around and even stand. **"She is a very determined child!"**

Physiotherapy: When Jeevna is asked to describe her physiotherapist Jackie, she beams a huge smile, puts her thumb up and says **"Good!"** Jeevna and her big sister Kangna think Jackie is very kind. Surjeet explains how Jackie has helped. **"We had been shown how to get Jeevna's prosthesis on and off in the hospital. When she got home, our goal was for Jeevna to walk. Jackie helped us know how to get there. She told us, 'You have to hold her carefully'. She taught Jeevna exercises and how to use the walker."** Once Jeevna could walk, Jackie's visits stopped, then re-started after Jeevna's surgery on her other leg in March of this year. Her leg had to be broken, then re-set and fixed with pins. She currently has a metal 'cage' fixed to her lower leg, with fittings that have been gradually tightened over the last few months. Surjeet continues, **"Jackie visits at home and at school, helping us deal with it. Giving us tips we wouldn't have thought of. She got Jeevna to clap when she was standing, so she had to let go of the walker and take all her weight through her legs."** Jackie and the family are meeting Jeevna's teachers before school starts in September, so that everything runs smoothly for Jeevna at her new school. Surjeet says they value the consistency of having Jackie as Jeevna's physiotherapist.

Future: The ultimate goal is for Jeevna to walk without a walking aid and to join in every day fun activities such as swimming, gymnastics, dancing and yoga – the same as her sister. Both girls spontaneously demonstrate the 'crab' position on the floor! Surjeet describes the mental challenge for parents is **"wondering how she is going to get on in society."** However, he is adamant that his daughter will enjoy a full and active life and the family's approach is to **"normalise"** Jeevna's experience. He reflects on a sign he saw a few years ago on a train in India. **"It said the carriage was for 'Differently abled people' – what a nice way to put it. It's so much more positive!"**

Surjeet, Jeevna and Kangna met Joanne Vaughan from Locala's Engagement Team on 26.7.22. Surjeet gives full consent to share Jeevna's story and provided the photo.