

Case study

Oscar – Age 5

Oscar was born with Tibial Aplasia-Ectrodactyl, a congenital condition that causes limb malformations. Oscar is affected on the right side of his body with a missing tibia, a short and twisted fibular and a cleft hand. He had an amputation of his right leg as a baby.



Limbformation



Oscar is a young child with a big personality who spends much of his time fearlessly climbing and jumping! This bubbly five-year-old kept everyone entertained at a recent LimbPower get together.

Oscar has Tibial Aplasia-Ectrodactyly, a congenital condition that causes limb malformations. Oscar was born with the right side of his body affected: he was missing a tibia; had a short and twisted fibula; fewer bones in his foot and a cleft hand (ectrodactyly) meaning that he doesn't have some fingers and no hand bones.

Rachel, Oscar's mum, first discovered something was wrong at her 20-week antenatal scan because there was a discrepancy between the length of Oscar's bones. They received the official diagnosis when Oscar was nine-months-old, but, because there were so many different variations, Rachel was unable to get proper advice.

Decisions about treatments and surgeries are very personal to each child and their family. However, Oscar's parents decided very early on to amputate Oscar's right leg above the knee. Because this was done before Oscar had any real memory of his lower right limb Rachel says "It's his normal".

A child starting school is a momentous occasion for any parent, but if that child has limb differences, this time can be full of uncertainty. Oscar started in Reception recently and it's been a baptism of fire for his parents. Rachel has found pre-empting the situations that Oscar might face in an environment that she's not familiar with very challenging, so she advises that communication with the school is crucial. While schools have the best intentions for their pupils, they will not necessarily have the required experience of limb difference or prosthetics to make the best decisions.



Rachel recommends that you make the time to explain things and try and understand as much about the environment and the school day as you can.

Oscar and Rachel are very much part of the LimbPower family. Oscar came along to LimbPower's Manic MaraFun event in 2017, a fun day out for the whole family with a

teddy bear's picnic, a mini sports day, face painting and wall climbing.

Oscar very rarely stops and when he's not jumping and climbing, he loves trampolining, swimming and horse riding. We can't wait to see what Oscar gets up to next!



LimbPower, Whitecroft, Tandridge Lane, Lingfield, Surrey RH7 6LL T: 07503 030702 E: info@limbpower.com W: www.limbpower.com

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 Department of Health