

# Case study

## Kyra – Age 9

*Kyra was born with Proximal Femoral Focal Deficiency (PFFD) of her left leg. The congenital limb difference has seen Kyra deciding on limb lengthening surgery with Dr Paley.*



**Limbformation**



**At nine years old, Kyra loves spending time with her friends and especially enjoys scary rides at funfairs. Her ability to confidently describe her limb difference and detail the extensive surgeries she has had so far is remarkable.**

Kyra has Proximal Femoral Focal Deficiency (PFFD), a rare congenital condition that can affect the pelvis, the hip bone and the proximal femur. In Kyra's case, she was born with her left femur 50% shorter than her right as well as a deformed hip and ankle. This was identified during a check-up shortly after Kyra's birth because she only had one crease on her left thigh, yet there were two creases on her right. It was a hugely worrying time for her parents, who spent hours researching the condition to understand what this would mean for Kyra in the long-term.

Decisions about treatments and surgeries are very personal to each child and their family. Kyra and her parents opted for limb-lengthening surgery after meeting Dr Paley, one of the world's most experienced limb lengthening surgeons. Before Kyra could embark on the first of her limb lengthening surgeries, she had to have an operation to reconstruct her hip to make it stronger, which is needed for the lengthening operation. The family then raised the funds to pay for the lengthening treatment, under the care of Dr Paley at the Paley Institute in Florida. Kyra had surgery to put a telescopic rod into her femur, followed by 60 hours of physiotherapy after the operation to help lengthen the tendons and muscles. The treatment has gone very well, with Kyra's left leg length increasing by 5cm. The next step for Kyra and her parents is fundraising and planning for the second lengthening surgery.

Kyra's parents discovered LimbPower through Facebook and attended the LimbPower Junior Games at Stoke



Mandeville. The event gave Kyra the opportunity to try and receive coaching in a number of sports and it was here that she met two other children with the same condition as her.

Kyra's experiences have inspired her to help people in a similar situation to her. When she is older, she wants to be a corrective limb surgeon and care for children born with similar conditions.

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*LimbPower exists to engage amputees and individuals with limb impairments in regular and sustained participation in physical activity, sport and the arts to improve quality of life and to aid physical, social and psychological rehabilitation. To find out more about how we can help you, visit our website. LimbPower is a Limited Company No. 09513024 Charity No 1132829*

  
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