Case study 7

Gracie* - Age 7

Unilateral PFFD and Fibular Hemimelia





Gracie was born with unilateral PFFD and Fibular Hemimelia. The family have always approached Lucy's disability with a very positive 'can do' attitude. When Gracie was 20 months old the family opted for amputation, knowing that lengthening was not an option. There was a great deal to consider before making this decision but they felt that the reasons for amputation far outweighed the reasons for against.

It was only when Gracie was born that the family became aware of her condition, it took several weeks for them to get a correct diagnosis but the most important thing to the family was that she would be able to walk. Her siblings were supportive and compared her to the CBBC presenter who had a 'short' arm.

Gracie received her first prosthetic leg at 14 months old, pre-amputation. She leaned to walk quickly and has always been happy to wear her prosthetic. the family have always encouraged Gracie to have a go although they did have concerns in the early days as to how sport could be adapted for her. There were negative gymnastics coaches in the early days who were unable to see a way to include Gracie but the family carried on. Gracie started swimming at three and she continues to swim as well if not better than others in her swimming class.

In 2015 on Disability Awareness Day, Gracie discovered the martial art, Kuk Soon Won. Along with her older brother she showed a great deal of interest. It took a year for her parents to overcome the negative comments they had received from the gymnastics teacher but eventually they asked if Gracie could join in.

Welcomed with open arms, Gracie hasn't looked back. Since joining Widnes Martial Arts she has attended 5 tournaments and has medalled on each occasion. She is

currently the only amputee who competes in Kuk Soil Won. It was her instructor that initially asked if there was possibly a limb or knee that could benefit Gracie as her everyday limb had limitations.

It was at this point that the family spoke to their prosthetist and were made aware of the Children's Activity Prosthetic Fund. Gracie received her first activity limb at the

beginning of September 2017. Gracie learnt to run for the first time. the family saw straight away the change in Gracie and the freedom that an activity limb gave her, before she had only been able to propel herself along in a hopeless attempt to keep up with her friends. Finally Gracie is starting to look forward to Sports Day.

The family have always loved and accepted Gracie for who she is, being inspired by her strength. They are clear that the information they have received along the way has helped them to support Gracie, particularly at times when she has required counselling because she wants two legs. Support from other families that they have met at different events has helped, as has the optimism that Gracie has felt since she has had an activity limb.

Gracie currently takes part in swimming, Street Fit, Kuk Wool Won, Drama and Multi-sports. She recently attended a Fundamental Skills Workshop held by LimbPower and was able to take part in competitive sports for the first time with children with similar differences and using activity limbs. The family felt that Gracie felt very safe in an inclusive environment and learnt how to get the best from her activity limb.

This child received their activity prosthesis through the **Children's Prosthetic Fund** from the Department of Health and administered by LimbPower. Please ask your Limb Centre if you want to know more about how to access this fund.

*Please note that the names of the children have been changed to protect their identities.

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