



Scott Fund Trust grant recipient, Alice Robinson.

GRANTING A CHILDHOOD

A marine biologist, a ballet dancer and a rubbish truck driver. These are the things five-year-old Alice Robinson wants to be when she grows up.

It resembles most children's line-up of vocational possibilities. Possibilities that to them seem as achievable as the easy ones – like climbing the slide ladder at a playground, or getting up off the floor.

But for Alice, who was born with generalised low muscle tone and very loose ligaments, supposedly 'easy' activities like mounting a kerb, going up stairs, climbing in and out of the car and sitting up straight are far more challenging.

"Alice struggles to 'fire' her muscles much more than other children her age, so she tires very easily," Alice's mum, Meg explains.

Alice's loose ligaments caused hyper-flexibility, making her a bit like a baby giraffe trying to stand for the first time.

"Except that for Alice, it was 'baby giraffe stuff' all the time."

Up until the age of 28 months, Alice used a walking frame along with special orthotic splints and boots to aid her standing and walking. But early in 2018, Alice received a grant from the Scott Fund Trust – a charitable fund set up under the Will of the late David Henry Scott and administered by Presbyterian Support East Coast. The income of this Trust is used to provide educational or vocational assistance to people under 21 who have disabilities and live in the Hawke's Bay and Gisborne regions.

The grant enabled the purchase of a TheraTogs suit for Alice – a specialist orthotic undergarment that can be customised to support and improve postural alignment and stability, movement ability and precision, joint stability and prolonged muscle use.

For Alice, who was three at the time, it meant a new lease on life.

"When she began wearing the suit, Alice's body was still quite crooked, and she didn't have much stability," Meg says. "She couldn't run and unless she was walking around the house, she needed to hold someone's hand for support.

"I noticed an immediate change in Alice. She told me the suit made her feel more confident."

The first time Alice wore her 'Cuddle Suit' to the playground, she climbed straight up the slide ladder unaided – something she had never been able to do before.

"She was so proud," Meg says. "The suit has allowed her to experience many such wins, which makes her want to experiment with other physical tasks and movements. She has achieved things I had never dared hope for!"

There have been other wonderful benefits. Alice's need for pain medication is now minimal. The suit's support of her diaphragm helps her to recover quicker from colds and coughs, which would previously last for months. The support of her pelvis, along with the ability to be more active, has drastically improved her bowel health.

Alice is now walking, running, dancing and even riding with Riding for the Disabled (RDA).

"Alice feels that she is a very capable person," says Meg. "The suit boosted Alice's development in a non-invasive way, so she owns all her physical achievements herself. We are so grateful for the grant from the Scott Fund Trust."

It's as if Alice was granted far more than just funding for a suit.

And that is priceless.

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Alice with her mum, Meg.