

SOME OF OUR CHILDREN

Sam was born with cerebral palsy, a degenerative disease that affects him physically and mentally. He depends on his parents, caregivers and his wheelchair for mobility, as his body is unable to mobilise itself. However Sam has a wonderful opportunity – he is a user of the Hart Walker, a frame that supports his body allowing him to walk upright and independently.

Sam, 12, has had his walker since he was four, when they first became available in New Zealand and when he was first able to walk. The frame is designed so that every point of the body utilised in walking is supported. Sam's torso is supported so that he can stand up straight; supports also run down from the waist to each leg, bending at the knee and ankle where it connects to special Hart Walker walking boots. As Sam grows, each part of the walker must grow with him, adjusting to his lengthening legs, growing feet and changing height. These adjustments are made by a trained orthotist (specialist in planning, making, and fitting orthopaedic braces) at least twice a year to accommodate Sam's growth.

Orthotist Stuart Kerr visits from Sydney every six months to measure the growth and progress of Hart Walker children so he can make any adjustments necessary to the frame. Stuart gauges any growth; he then observes how they are walking. The design of the frame means that children are forced to walk properly, which is sometimes what makes the process of doing so harder, but what also provides it with numerous physiological benefits.

Physiotherapist Jennie Andrew attends clinics in Wellington and Auckland with Stuart. Her enthusiasms for the benefits of the Hart Walker are numerous. She says that the way the walker promotes specific movements improves bone alignment and correct muscle development. Neither of these is possible when cooped up in a wheelchair. The frame's support of the hips, feet and legs provides "control and stability for independence" she says.

This independence is a great opportunity for children like Sam, who are often completely dependent on others. They are capable of standing and walking to where they would like to go. This also offers fantastic social advantages. All of a sudden they are able to be at the height of their peers and interacting.

Jennie talks of a Hart Walker user she sees in Auckland who, at eight years old, walks to school and runs through puddles. Taylor, who attended the same Johnsonville clinic as Sam, usually leaves her frame at school where she uses it to walk to the library with her classmates. Sam's father, Dave, says that Sam absolutely loves his walker, especially in the summer when he can use it outside.

These advantages are amazing for children with cerebral palsy and it is evident on the smiles on their faces while they use it, and the people who experience seeing the difference. Stuart says that it is amazing just to see the children puffed out from the exercise, something they almost never get.



Physiotherapist Jennie Andrews with a delighted Sam in his newly adjusted walker, and Dave, Sam's father.

Shyla-Mei is a five-year-old girl living in Rotorua. She has severe cerebral palsy resulting in significant disabilities that interfere with control of posture, balance and movement. The cerebral palsy affects her total body including the muscles of speech and swallowing.

Despite these physical difficulties, Shyla-Mei is an alert, responsive, intelligent little girl with a great zest for life. She has some speech, understands commands, and is in Year 2 at Malfroy Primary School. Shyla-Mei and her family are very motivated to have her walking and the Hart Walker offers her the opportunity of achieving this goal.

After learning of Shyla-Mei's need, Past Council Chairman Sheryl Jensen in Rotorua approached her own Sulphur City Lions Club and members became very passionate and supportive of the project.

"It's just so awesome," says Shyla-Mei's mother, Nicole. "She walks all around her bedroom and can open her drawers herself. It's so cool, how it's changed how she sees things. I'd take her walking, but I'd get tired and have to stop. She'd get so cross! Now I know her limbs are in the right position for walking, and I feel so much better knowing her muscles are working properly.

"It's such a buzz to see her in it. Even when she is tired she doesn't want to get out," Nicole said. "There are so many things we can do together that we couldn't do before. We play Tag, kick a ball, and the other day we picked flowers together for the first time."

Shyla-Mei has now built up her strength and takes the Hart Walker to school. Lions Clubs in Rotorua continue to stay close to and provide practical support for Shyla-Mei and her family.



Shyla-Mei with Lion Sheryl Jensen and her mother, Nicole



Nicole and Shyla-Mei take a walk in the garden to see Blackie the hen.

A letter from Shyla-Mei's Mother

On behalf of myself (Nicole), my partner James and most of all our daughter Shyla-Mei, we would like to say a HUGE "THANK YOU" to all who have been involved one way or another in the process of getting Shyla-Mei's "Most AMAZING" piece of equipment we have ever come across "The Hart Walker." It's so beneficial, actually aids our daughter with her walking in a good way instead of causing bad posture, no support, and an unnatural way of walking which is all we had with previous walking frames, so we would physically walk Shyla-Mei ourselves, because we think "why should she miss out?" We are quite small people ourselves and this daily task was becoming so hard to do for any long periods which was so frustrating for us as parents to see our very determined little girl keep trying to stand up and keep on going, but having to say "No, mama's got a sore back, gotta have a rest man!"

So when we heard that the Lions Club would fund Shyla-Mei's Hart Walker it's been honestly an answer to our prayers, just to see the joy in her eyes when she's upright, independent and mobile, a dream come true for us, and being hands free we were able to walk side by side holding our daughter's hands for the first time in five and a half years which made us so happy we could cry! The Hart Walker has given Shyla-Mei a new found independence and has opened up a whole new world for our daughter; she is able to experience life at a whole new level now. Her eyes can be fixed on higher horizons! (being up-right), the Hart Walker has given her this.

Thank you to Sheryl Jensen for all your help; the Rotorua Sulphur City Lions Club and the other supporting Rotorua Lions Clubs. What a bunch of amazing people who really did understand how stressful things can be in our situation; they made this process as smooth as possible and it has been a pleasure!

FANTASTIC LIONS CLUB!

Thanks again Nicole, James and Shyla-Mei.

Alyssa and her twin brother Michael were prematurely born at 27 weeks, weighing one kilogram each. Alyssa was diagnosed with cerebral palsy soon after birth and it was obvious that she was going to need a lot of help.

Her parents, John and Donna, obtained help from an Australian doctor who specialised in helping children with this condition. He immediately put Alyssa on to an exercise programme requiring two hours therapy a day, seven days a week.

Opunake Lakeside Lions become involved with Alyssa's therapy when she was 12 months old when her grandmother, a member of the club, mentioned that she needed to be exercised daily.

Eight members volunteered and for three years two would travel daily to Oaonui to assist Donna McCarty with the exercise therapy - initially in the family home then later in the Oaonui Hall, as there was more room for the equipment they were using.

At five years old, after trying many different walkers, the Hart Walker proved the best, and Alyssa went to school in the Hart Walker every morning, walking up the corridor to her classroom.

Her exercises continue twice a week and this bright little girl, who takes everything in her stride, is making steady progress.

Opunake Lakeside members found the sessions very rewarding and could slowly see an improvement in Alyssa's progress. Alyssa loved books, especially Nursery Rhymes, and the Lions members all read to her during exercise sessions as it took her mind off the therapy she was receiving. One member recalls that Alyssa knew all the stories and nursery rhymes and knew if you had skipped a page.

The Lions members all loved Alyssa and she got to know them all so very well. Alyssa is a very intelligent little girl with very dedicated parents and grandparents and the entire club are very interested in her progress and proud to see her succeed.

Now seven, Alyssa has just been re-fitted with a new Hart Walker. She had been out of her walker for some months, following an operation, and having become too tall, an adjustment was necessary. Alyssa was clearly ecstatic to be back in her walker. Her mother Donna said she has had other walkers, but the Hart Walker is by far the best.



Alyssa meets International President Al Brandel at a clinic in Wellington, where she was delighted to be back in her Hart Walker.



Wheelchair-bound Alyssa before the re-fitting.

Hayden , 14, has cerebral palsy and he is blind. He was fitted out with his first Hart Walker at age five, but he has been without one for almost a year, as he had become too tall for his original walker.

Hayden has now been fitted with a newly developed heavy-duty walker, the first in the Wellington region. It truly was a transformation and Hayden's face said it all, as he went from his mobile chair to the new, heavy-duty walker. Suddenly upright and able to move independently, Hayden clapped his hands and laughed in joy. And life now, will perhaps become a little easier for his grandparents, Peggy and Arthur Foote, who care for Hayden full-time.

Hayden suffered brain damage at birth. He attends Kimi Ora School for Physically Disabled Children in Thorndon, Wellington – and is also mainstreamed part time at Thorndon School. He has a very busy schedule, says grandmother Peggy.

“The carers at Kimi Ora are wonderful; they take him on all sorts of outings every week – they go to the rugby, and swimming - he does backstroke. He goes horse-riding (with Riding for the Disabled) every Wednesday – he's very busy.”

The Footes paid for Hayden's last Hart Walker, but his new heavy-duty one has been bought with assistance from the combined Lions Clubs on the Kapiti Coast. Hayden's condition is recognized by the Accident Compensation Corporation and his caregivers receive some assistance in the way of taxi-ing Hayden to school, nappies, and respite care – but no financial help as such, is given to them.

A letter from Hayden

Hi There

My name is Hayden Thomson. My Gran is writing this message to you as I cannot communicate. I would like to thank everyone involved that has made my new Hart Walker possible. I am so grateful to you all and overwhelmed by your generosity.

My Hart Walker means so much to me. I will be able to interact with family and friends at their level again. I love the freedom of walking about and having fun with everyone.

Thank you for making this possible

Regards

Hayden Thomson



Watched by President Al Brandel, Hayden shows his delight at being upright and mobile again.

Best Christmas present ever

Dear Lions

On behalf of our family we would like to express our huge thanks for the donation of a Hart walker for our son Owen. Owen is five years old, has just started school, and is severely disabled. He was born with no apparent issues but at six weeks old was diagnosed with microcephaly, a disease that results from the failure of the brain to grow properly during infancy and childhood. His prognosis was poor and worsened when, at the age of just five months, he began having epileptic seizures and regressed further in his development. Owen is on permanent medication for seizures, cannot eat solid food, and suffers from low muscle tone throughout his body.

Despite all of this he is a happy, determined child. Last Christmas he learned to sit up by himself which has made him stronger and more able to interact with other children, but what he has really wanted to do since then is learn to walk.

He has had a "conventional" walker since he was three years old but has never had the strength to move it. Owen cannot speak and has a few gestures, but he makes it clear that he has a mind of his own and places he wants to go. Until now, he has relied on the understanding of carers and family to achieve this.

We became aware of the Hart Walkers through our local Dunedin parent-run support group for families with children who have cerebral palsy. Although Owen does not have cerebral palsy, we were impressed by the Hart Walkers and how the children who have them seem to be doing so well in them. We have been practicing stepping with Owen in the hopes that he would qualify for the Hart Walker programme, and this year we applied to the Lions.

Owen received his Hart walker on December 13th at the Dunedin Clinic. There, we got to meet a few of the wonderful people who helped to achieve this gift for Owen, but we are aware there are many others whom we did not meet but would love to thank. Owen was very excited and could not wait to try the walker. He could not work it out right away, but later that day made a few steps, and on the following day he had figured it out and was walking, by himself, for the first time! You should have seen his face, it was so clear that he was pleased with himself and proud of his first steps.

The Hart Walker is different to other walkers, and is not funded for children through the health system. Owen struggled with a traditional walker for two years without success, yet within one day, he could make beautiful steps with the Hart Walker. This is because it helps him to co-ordinate his left and right legs to make steps, something most of us have taken for granted since we were toddlers.

Thanks to the generosity and hard work of the Lions, our son can now walk tall alongside his two brothers, and make his own decisions about where he wants to go. So thank you, once again, for the best Christmas present a parent could receive: a happy child making his first steps.

Rob and Caroline Day



Owen explores the Christmas tree - the Hart walker allowing him to get really close up. Owen has a vision impairment and likes to touch and immerse himself in something to explore it.