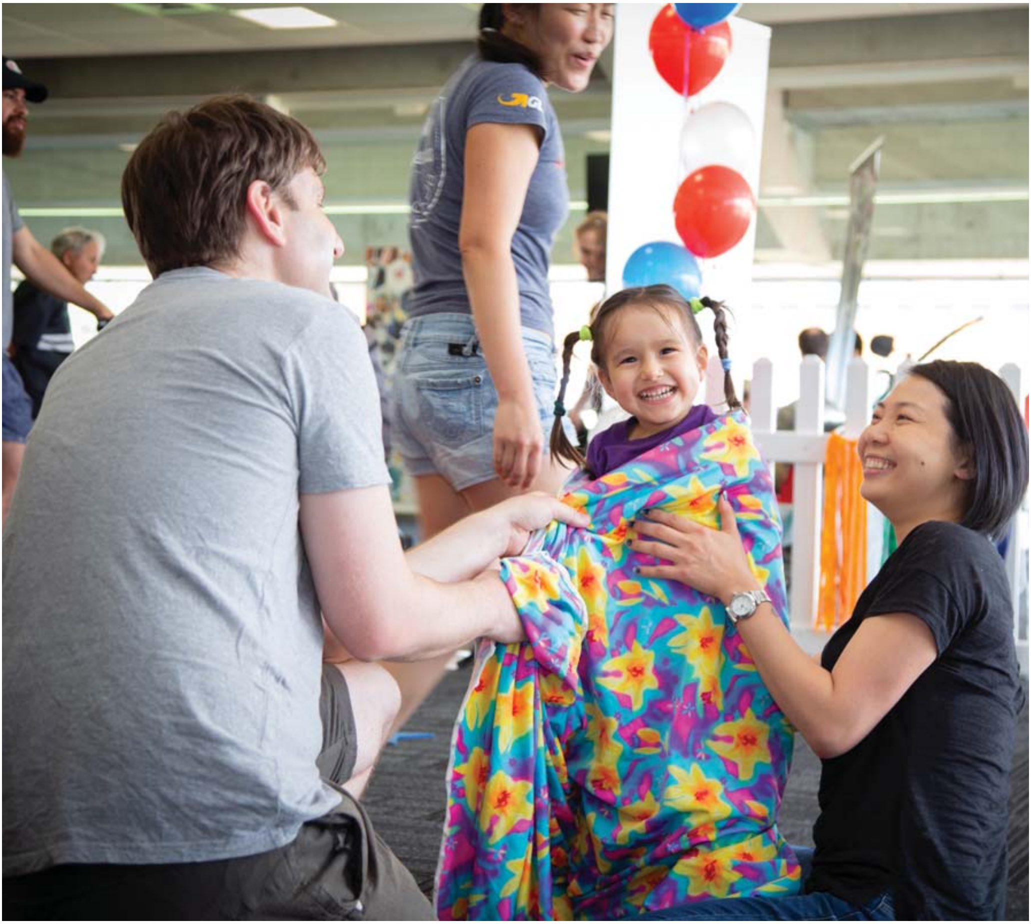
The Review

Official Magazine of the Cerebral Palsy Society March 2019



Cerebral Palsy Society
freedom & choice

Cerebral Palsy Society

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Index

News From Our CEO

I hope this issue of the Review finds you enjoying this long, hot Kiwi summer – it certainly has been a scorcher!

2019 has started with a flurry of activity from the team at the CP Society. We recently held our first ever 'Give it a Go Day' in Auckland which was an event which aimed to give children with disabilities an opportunity to try new activities. It was lovely to see so many young people trying new things and having lots of fun doing it! Following the success of Give it a Go Day we are looking at ways we can possibly replicate this type of event in other parts of the country.

We have also been fortunate to recently host world renowned physical therapist Pia Stampe, who has toured the country holding workshops and family meetings based on her therapeutic technique which seeks to harness neuroplasticity in children to enhance outcomes from physical therapy. In this issue Gemma shares with us some of the highlights of this tour and Pia's decision-tree model.

We would like to encourage members with CP to consider applying for a grant for larger items which help with the management of their condition. This programme is designed to help you access things that might otherwise not be financially feasible. If you would like more information on our grants visit our website or call 0800 503 603.

As always, we welcome your feedback, so please don't hesitate to reach out with any thoughts on how we can improve the way that we can better provide services to you.

Finally, our thoughts are with everyone affected by the horrific events of the Christchurch shootings. I'm sure you would agree that this act of cowardice is not reflective of who we are as a country and people with these attitudes and viewpoints are not welcome in our communities. If there is anything that the Society can do to offer extra support at this very distressing time, please don't hesitate to let me know.

Gilli Sinclair
CEO, Cerebral Palsy Society.

Wheelchairs Get Some Bling At Give It A Go Day!

Pimp my Ride, a stall where kids could decorate their wheelchairs, was just one of the activities on offer at the recent Give it a Go Day the hosted at Mt Smart Stadium in Auckland by the CP Society.

The free event attracted hundreds of families with children with a range of disabilities to come along and try different activities as well as have some good old-fashioned fun!

The event included a wide range of activities designed to appeal to a broad range of kids, from wheelchair basketball and mini car and bike track, to cupcake decorating, martial arts, music and art activities and much more.

Family Support Manager, Gemma Overton, who organised the event said it was all about having a great day out, in an inclusive and non-threatening environment without any cost to the families.

It wasn't just the kids who got to take part either. Give it a Go Day also included a parent corner which offered nail pampering for mums and pies and mini golf for dads.

All activities at the event were free thanks to the generous support of all suppliers who got behind the day.

"We have been so humbled by the generosity and willingness of people to help with making this event possible," said Gemma.

"We were especially grateful for the support of Auckland Stadiums which provided the use of the East Stand of Mt Smart stadium for free.

This was the first Give it a Go Day, but given the success of the event, the Society is looking at the viability of making it an annual fixture on the Society's calendar.

Fundraising Update

By Sue Lewis- O'Halloran

Andy, from NZ Safety Blackwood & Gilli

Goodman CEO, John Dakin & Gilli

Since the last edition of The Review, we hosted a reception in November, to thank and honour Goodman, the global partner of our Steptember campaign, as well as teams and individuals which achieved massive targets. Over $973,000 was raised to support CP programmes and research. We will be hosting Steptember 2019 and will let you know more details as soon as we have confirmed them.

One of CP's key partners, Edible Blooms, ran a Christmas initiative and raised over $900 for us. This is in addition to the many gifts they give us, including many Christmas tree bouuets for our Steptember reception. Thank you to Sarah and Edible Blooms!

We're also engaging with secondary schools throughout New Zealand and many are stepping up to get involved in 2019 – we are so fortunate to have their support!

In March, thanks to arts patron Sue Doherty, we'll be hosting a sale and auction of the works of Jimmy James Karatouras, with a portion of the proceeds going to the Society. This private event allows us to showcase the Society to people who know little about us and whose involvement could really help us to grow, in both profile and resources.

John , Jannette from T&G & Gilli

The team from Goodman

We will be sure to include photos of the event in the next issue of The Review. Special thanks to Sue Doherty and Jimmy K for supporting us in this way.

At a recent fundraising conference, hosted by the Fundraising Institute of Australia, we learned the importance of developing a “culture of philanthropy” so that is on our agenda for 2019.

Thanks to each and every one of you who honours the Society with your gifts.

Join the CP Society Grants Committee

We are looking for three new members to join the CP Society Grants Committee over the next 18 months. The committee needs one person with a lived experience of CP, one with a family experience and someone with a therapy background. These are volunteer positions.

The role of the Grants Committee is to assess the grant applications received from our members and decide which should get funding. The Committee meets every month by phone and assesses peoples applications. The meeting is usually around an hour but there is a also some pre-reading prior to the phone meeting required . If you are interested in potentially joining the committee or would like more information please get in touch with Gilli giilli@cpsociety.org.nz or 021 177 7517

It’s Time For A Change – An Overview Of Dr Pia Stampe’s Visit

By Gemma Overton

Have you ever had that ‘aha’ moment when listening to somebody speak? Finally locating that final piece of the puzzle? Sitting in a hotel conference room with therapists and parents, listening to Dr Pia Stampe present on the theory behind neuroplasticity and how theory is put into practice at her Private Paediatric Clinic ‘Step by Step’, was my most recent ‘aha’ moment.

Dr Stampe is a physiotherapist originally from Denmark who resides in Rochester NY. She received a bachelor degree from University of Copenhagen 1981 and her Doctor of Physical Therapy Degree from AT Still University in 2008. Pia has practiced paediatric physiotherapy throughout her career and has extensive teaching experience that includes Brachial Plexus Injury, EMG Biofeedback as well as Cerebral Palsy. She owns Step-By-Step, a busy paediatric practice servicing children in early intervention, preschool special education, in home and community-based settings, as well as outpatient settings.

Pia, together with the late Dr Karen Pape, her long-time friend and mentor, developed a framework around intensive therapy called ‘Step by Step’s Key to CP’ and, as part of Dr Pape’s legacy, Dr Stampe is now at the start of her journey to share this knowledge with therapists and families around the world. The Cerebral Palsy Society recognised that members with younger children and teens had a need for intensive therapy to be available in New Zealand and recognised the current gaps in the system. So, through a parent connection to Pia and Step by Step, the Society arranged to bring her over to present the program to therapists and parents in New Zealand.

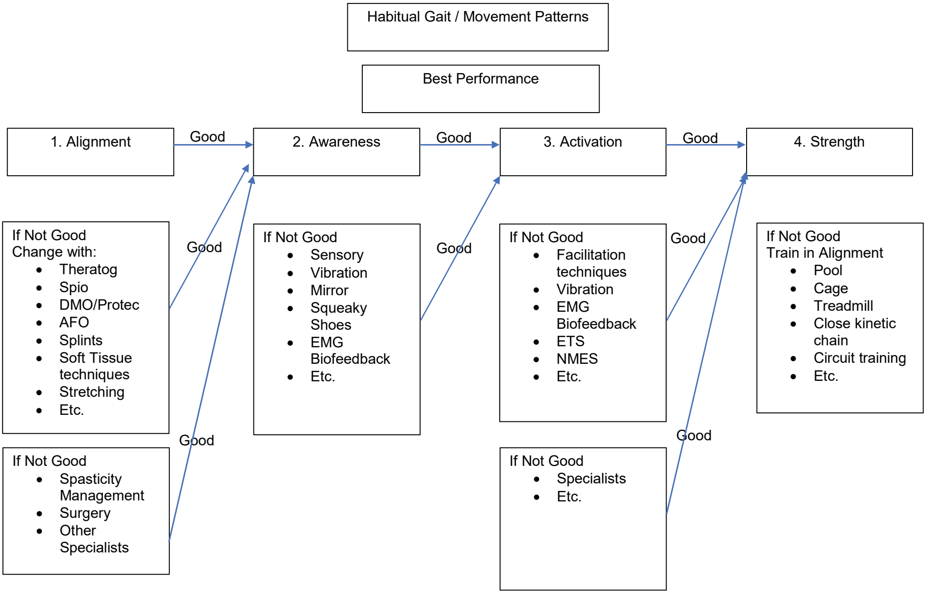
On the 11th February the Society's office doors opened to therapists and families who had come to hear Pia present on the Step by Step ‘Key to CP’s ‘program. Pia’s tour included both a half-day and two week day workshops with therapists and many meetings with parents in Auckland, Wellington and Christchurch.

Her work focuses on windows of increased neuroplasticity in children where significant gains in their physical therapy can be made. While Pia’s technique is unique, she says that many New Zealand therapists already have many of the tools in their toolbox required to implement her programme and see big gains in children with CP.

For me, meeting Pia and seeing her work has made me realise how important it is that we work at a government level to do everything we can to ensure that this type of therapy is more readily available to children with CP. We need it to be more accessible and affordable and integrated into our children's healthcare journey. Having met with many of the therapists that Pia was working with, I am in no doubt that they are already onboard with this approach and that it is at a Ministry (MOH, MOE) level that we now need to concentrate our efforts to bring about real change in this space.

I am still formulating what advocating at this level might look like, but I imagine it involves a presentation showing case studies, modelling around the costs of intervention. Critical to this picture is the cost on people with CP if we don't look to implement this kind of intervention model. What I have learnt is that this type of model does not cost more, so it's more about a redistribution of resources rather than necessarily seeking additional funding.

If you would like to know more about Pia's techniques, or would be interested in being part of a working group to advocate at a Ministry level, please don't hesitate to get in touch with me gemma@cpsociety.org.nz



Dr Stampe's CP decision making tree

Wellbeing Trend Reflected in CP Projects

The concept of wellbeing has received considerable attention in recent months. The government has committed to incorporating a “wellbeing budget” into their accountability measures. This initiative examined areas such as how policies impact key points like mental health, environmental protection and creating equity amongst minority groups. Wellbeing is also an increasingly important measure for cerebral palsy (CP) research and how this information is distributed meaningfully to the community. Research distribution means both into clinical practice such as physiotherapy practice and the day-to-day lives of individuals and their families.

The Cerebral Palsy Society (CPS) is partnering with a number of projects that aimto identify core wellbeing measures for people living with CP. Increasingly, health research is being shaped by co-design where people with lived experience are designing, supervising and implementing research alongside the academics and clinicians. This emphasis on co-design has helped to shape every aspect of the research process from choosing a relevant research topic to producing all research material. A few examples of co-design include maths apps for CP, developing new home rehabilitation programmes and new concepts of wellness and severe CP.

The Centre of Research Excellence in Cerebral Palsy (CRE-CP) is an Australian project on which the CPS is collaborating. This group aims to improve the health and wellbeing of all people affected by CP and their families. The researchers, clinicians and allied health professionals are joining forces with parents, carers and people with CP in an effort to bring about meaningful change in the management and treatment of CP. Some of their research initiatives include new measures of quality of life from the parents’ perspective, a pilot study of the effect of Gabapentin on CP pain, research into the life goals of young adults with CP and investigating the effectiveness of saliva control treatments. Research topics are prioritised around the areas of CP that individuals and families feel are most important to them.

The CRE-CP has developed a number of community and education plans including producing a podcast on different topics relating to CP and creating better quality of life. Topics include how to measure quality of life, sleep and CP, staying well after surgery, application of rehabilitation robots, mental health of parents and hip surveillance. Other resources include fact sheets for GPs that incorporate information about the condition and how it can affect the baseline health such as complicated asthma presentation and unusual blood pressure readings. There is a series of sixteen factsheets, each covering a different feature of CP. The CRE-CP is a great example of collaboration in action.

If you would like to find out more information or receive copies of any fact sheets, please feel free to email me at amy@cpsociety.org.nz . You can visit the CRE-CP website directly at cre-cp.org.au

Shampoo Bars – No Need For Bottles When You Have Bars

Cerebral Palsy is an unpredictable condition that can manifest in many different ways for those who have it, often making the simplest, somewhat mundane tasks like personal hygiene frustratingly difficult for some - until now thanks to Ethique.

Ethique, an eco-friendly New Zealand owned ethical beauty company founded by biologist Brianna West, first opened its doors in 2012, determined to rid the world of plastic waste. A business that began in a kitchen has now grown into a successful award-winning international corporation that exports all over the world gaining the attention of celebrities like Britney Spears and Ashton Kutcher along the way.

One of Ethique's most sought after products is their Shampoo bars, all of which are sustainably sourced and naturally formulated. Because of the company's commitment to remain eco-friendly, none of their products harm the environment and their packaging is all plastic free. Ethique's shampoo bars tick all the boxes if you are someone looking to reduce your impact on the environment while keeping within your budget, and without forgoing the comfort and convince that your average bottle of shampoo offers.

Ethique's shampoo bars are also portable, making them an instant travel accessory if or when required.

Apart from all these wonderful features, Ethique's shampoo bars also give people living with physical impairments like Cerebral Palsy their independence back ,simplifying what would have otherwise continued to be a frustrating ordeal for some who have the condition. The majority of people who have Cerebral Palsy struggle with their fine motor skills and range of motion, making a task as simple as squeezing some shampoo out of a bottle understandably difficult. However, with Ethique's shampoo bars this is no longer an issue. People with diminished capabilities can now also enjoy all the freedom and convenience able-bodied individuals have.

But don't take my word for it, try them out yourselves and see how much easier one of life's simplest tasks becomes. Enjoy the stress-free satisfaction of a good shower anytime, anywhere.

PDRLNZ Grant Story

The Physical Disability Rugby League of New Zealand (PDRLNZ) is a non-profit organization which aims to provide people with physical disabilities an avenue through which they can engage and play the game of rugby slowly normalising physical disability in the world of sport. PDRL employs a modified version of rugby to ensure people with a wide variety of physical impairments that affect either mobility, dexterity or functionality can enjoy playing the game they love, which, without these modifications, would not be possible. The PDRL's version of the game has all the physicality and intensity a standard game of rugby has and more.

In 2018 the Cerebral Palsy Society was proud to partner with the PDRLNZ and help them travel to and participate in the 2018 Emerging Nations Rugby League World Championships held in Sydney from the 6th-14th of October where they did very well. While the PDRLNZ were in Sydney for the Rugby Championships the Cerebral Palsy Society also assisted the team with their accommodations which ensured the PDRLNZ had a blast playing the sport they love representing and inspiring others like them to give it a go. The team unfortunately lost in final but despite loosing they were the true MVP's and winners because they gave it their all and left it all on the field.

If you have Cerebral Palsy and think you can't play the game, you love to think again and get in touch with the Cerebral Palsy Society apply for this grant and join the PDRL.

Join the MOH Consortium

The MOH Consumer Consortium is looking for a person with CP and a family member of a person with CP to join its group.

Disability Support Services want to involve disabled people in making decisions about Ministry of Health funded disability support services. The consortium provides a link between Disability Support Services and the people who use the services funded by thrm.

The consortium invites people representing national disability organisations to provide input and advice to Disability Support Services on its planning, policy and service development.

The Consortium meets twice a year and meeting agendas may include:

- Updates on Disability Support Services' projects and activities
- Presentations from other government departments, eg, Ministry of Social Development, Ministry of Education
- Requests for the Consortium's advice on:
- Development of DSS Strategic and Annual Plans and updates on implementation of these
- project implementation, eg, New Model, Enabling Good Lives
- issues of concern to the disability sector, prioritisation of these, and how these could be addressed
- Policy development
- Service quality
- Service gaps
- Improving collaboration between government agencies, between consumer organisations, and between government agencies and consumer organisations.

For more information on the Consumer Consortium or if you are interested in getting involved contact Cheryll Graham, Senior Advisor at Cheryll_Graham@moh.govt.nz.

Partnering with Parents in New Zealand to design eHealth for children with cerebral palsy

eGEMS

encouraging Growing hEalthy by Moving & Standing

An Invitation for parents of children with cerebral palsy

Participate in research to design a digital health intervention that gets your kids standing and moving.

✓ **Child's Age**
Between 5 - 12 years old

✓ **Child's Ability**
Needs assistance for standing & walking

✓ **Child's Equipment**
Has access to a standing frame

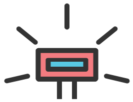
✓ **Parent's Equipment**
Home Internet access and a personal computer

The Details:

If you are a parent of a child with cerebral palsy and your child needs help to stand or walk (GMFCS III-V), you are invited to participate in a research study. The study aims to co-design an online programme with parents that will support their child's therapy programme at home, specifically to increase time in standing.

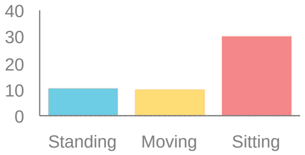
You are eligible to participate if you live in New Zealand and your child uses a standing frame as part of their usual care. Your child should be between 5-12 years old and you will need to have access to the internet through a personal computer or internet connected device from home to take part.

- Participation will be through online meetings from home
- Meetings will in English and include parents and researchers
- You will need to be available for online meetings between March - September 2019



wearable sensor

Your child will be asked to wear an accelerometer to measure their standing and sitting activities as part of this study



For more information or to participate

Get the information pack online or email Mindy Silva (see below)

Thanks for spreading the word

Please share this URL with interested families in your network -->**bit.ly/egems2019**

About this study

This study is part of a Phd project through The University of Otago Medical School, Research, Teaching and Rehabilitation Unit (RTRU)

To get the

Information Pack

copy the URL into your browser (it's case sensitive) → bit.ly/eGEMStart

or email mindy.silva@postgrad.otago.ac.nz

The study has ethics approval from the Health and Disability Ethics Committee Ref: 18/STH/181

Disability Swing Seat Grant Story

The playground has been and continues to be one of the most common childhood experiences/ pastimes experienced universally through most of the world. However, until now, this simple activity can be increasingly more difficult and sometimes beyond the scope of physical ability for people with physical impairments.

Park Supplies, New Zealand's largest stock supplier of park equipment for every kind of playground out there, has introduced the Disability Swing Seat. The perfect park companion for kids with physical impairments like Cerebral Palsy, giving them the ability to enjoy the playground and all it has to offer.

Addy Marsh applied for and recently received a Disability Swing Seat through a grant provided by the Cerebral Palsy Society. Addy applied for this grant because she wanted to be able to use the swings on her preschool's playground and have fun with her friends and now she is doing just that (see photo above).

So what are you waiting for? If you have Cerebral Palsy and want to experience all that the playground has to offer and have fun doing it, apply now for the Disability Swing Seat Grant through the Cerebral Palsy Society now.

New Zealand Census Review

The government is beginning preparation for the 2023 Census. One of the key things that independent reviewers are seeking is improvement in participation across all sectors of New Zealand society. In the 2018 Census, individuals living with disabilities and their families were not well represented in the participation figures and subsequent data collected. The Census is an important mechanism for deciding government policy and future funding initiatives. Therefore, producing a census that is accessible and responsive to changing disability demographics is important and necessary.

Recently, I travelled to Wellington to be part of a community consultation process, whereby individuals outlined possible improvements either in content questions or how the census is delivered. The independent reviewers are completing their report later in the year. New Zealand is committed to UN census guidelines. Therefore, the government is required to produce a census that is independent, meaningful to the population, and respectful of data privacy. If you have any comments about your experience(s) filling out the census, please feel free to email me and I can collate the feedback as part of the independent review. Here are some key aspects of the meeting in Wellington:

1. Future disability questions need to incorporate a broader range of disability levels and types. Particularly, around ‘invisible’ experiences. For example, going upstairs may not be the metric for assessing disability.
2. There needs to be better communication about census, results or subsequent surveys, that come from them such as their General Social Survey, and the housing review.
3. Government consultation with the disability and other minority groups needs to be meaningful and productive, with set outcomes and deliverables.
4. Digital and online services need to be encouraged, enhanced and accessible.
5. In the census, there are typically only one or two questions related to the experience of living with disabilities. Therefore, we need to ensure that it is a relevant and meaningful question, rather than arbitrary mobility questions.
6. The independent panel is meeting with a range of disability groups to enhance their representation, such as mental health support and learning disabilities.

If you would like any further information about the consultation process or the census in generally, please feel free to email me (amy@cpsociert.org.nz) or contact Statistics NZ.

Meet George

Gidday George here. I am a 22-year-old with cerebral palsy. My CP affects all four of my limbs but more so the left side of my body. I grew up on a farm south of Pahiatua in the Wairarapa with my identical twin Edward. It wasn't until my brother started walking and my parents questioned why I could not that I was diagnosed with CP.

However, I have never let this get in the way of what I want to achieve in life. I enjoyed the things any young rural kiwi boy would growing up playing outdoors and rugby! After finishing secondary school, I decided that in order for me to get a job and have a foot in the door I needed a degree. So I shot off to Massey University in Palmy where I completed a Bachelor of Business Studies majoring in marketing and, like most students, enjoyed the social side of university! I was interested in the marketing and advertising that surrounds different businesses.

However, I feel it was one of my other interests, travel, that led me to the job and opportunity I now have today. I decided after finishing my degree to have 6 months backpacking and traveling solo around South America. A daunting prospect most people would think, let alone for someone with CP. I was nervous at first but my desire to explore new places and cultures superseded this!

I had an amazing time over there and made hundreds of new amigos, tried my hand at Spanish and Portuguese and exotic foods such as Peruvian Guinea pig! There were perks for being a disabled traveller too. When I visited the Iguazu falls in Argentina, my Cerebral Palsy Society of New Zealand card got me free access into these incredible falls! ID's do come in handy! It was difficult at times to get around, especially with a 60 Litre backpack! But I proved to myself I can live independently and that I really can do anything in life I wanted to! After returning from my trip, I wrote a few travel articles and blogs, re-counting my amazing experiences. It was these real life accounts that set me up for the next stage of my life! A full-time job! I applied for many full-time marketing and advertising positions, most of them in Auckland. Before stumbling upon an internship role for a Company called Lifemark.

My written and blog work helped get my foot in the door with Lifemark. They are a company that campaign for homes and properties to be Universal Designed. This means that they are accessible to people from all walks of life, from your everyday families, to elderly people, and people with accessibility issues. I felt this was a great fit for me. It was a big move for me with Lifemark based in Auckland but luckily I had uni mates working up here as well, so we moved into a place relatively close to my work on K Road.

I also am, surprisingly enough, a Blues Rugby fan, so an Auckland move had other benefits! My role for Lifemark is as a Social Media specialist so I am required to write the monthly newsletter, blogs and manage social media pages. My first full-time job will have a lot of learnings although I am really enjoying my life up here in Auckland and now have a great opportunity to live my own independent life!

I consider myself a pretty normal guy with a normal life and hope that my story will inspire others kids with CP to not let their disability get in the way of what they want to achieve in life and understand that everyone has the opportunity to live an independent and enjoyable life! Also, if you would like to learn more about Lifemark the company I am now working for, follow these channels.

www.facebook.com/Lifemark or @lifemark on twitter or visit our website at www.lifemark.co.nz

Boccia Survey

Recently, the Cerebral Palsy Society asked our members for their feedback on how we can best shape the future of Boccia to help the sport thrive and grow within New Zealand. There were 33 responses from around the country and also a number of people giving me feedback anecdotally. The main theme from the survey is that there is a broad range of Boccia experiences within our membership. This includes extremely experienced players right through to complete novices.

- Some feedback people expressed interest in learning more about Boccia at both competitive and social level
- There was a strong desire for more local support for regional competition and participation.

Some of the main barriers to inclusion were the lack of local clubs and transportation to them. The Society is working to enhance the grass roots level of Boccia and increase player numbers throughout New Zealand. If you have any additional feedback on Boccia, please feel free to email either amy@cpsociety.org.nz or scott@boccia.org.nz

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Christmas Events 2018