The Review

December 2016

The Official Magazine of the Cerebral Palsy Society of NZ Inc

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News From Headquarters

It's hard to believe another year is coming to an end; summer is beginning and Christmas and the holidays are upon us!! Wishing you a lovely holiday time and a very Happy Christmas.

Many thanks to the board members from Essential Assets – Daniel Aldersley, Robyn Stent and Dave Thomas and Cerebral Investments- Anthony Smith and Brian Yee who have continued to provide excellent investment and entrepreneurial expertise and management providing the funds to ensure CPS provides support and services for you. Their time, energy and commitment to the Cerebral Palsy Society is remarkable, and we are extremely grateful for this.

The Cerebral Palsy Board consists of Peter Fergusson (President); Dave Thomas (Treasurer); Harvey Brunt (Vice President) and Anthony Smith, Bruce Brycroft, Jake Mills, Michelle Thompson, Michael Turner and Sally Thomas. I have really appreciated the collegiality, wise direction and strong work ethic of our voluntary Board of Directors over the past 12 months. It is exciting to move into our next stages of growth and development with a full component of skilled people.

The Board approved our strategic plan this year focusing on four main areas:-

Members - ensuring all programmes and services are developed with the intent of empowering members to enhance their lives

Funding - to ensure ongoing viability, sustainability and growth to support our asset base

Advocacy - to define strategies for the Society that empower members (based on clarification of purpose and core set of values)

People - to ensure members are empowered to enhance their own lives.

We are delighted to advise you the programmes are continuing to go really well. We have made some improvements- based on your feedback across all our systems. Over the past financial year, we have:

- Approved 69 grants for a range of equipment and opportunities by members, we don't fund ideas!
- Provided 312 members with 6,240 getThisandThat vouchers valued at $38,760.
- Provided 1,431 membership applications with 57,754 getOutThere vouchers valued at $208,550.
- Provided 541 membership applications with 25,700 getPhysical vouchers valued at $115,860.
- Provided 11 members with getStructured opportunities
- Provided 19 members with getUpAgain support
- Provided 62 trikes and is actively looking at walking trikes to assist our membership.

Special thank you to the Grants Committee who meet every month to ensure we have a transparent and fair process around the applications. Thank you for your time and energy.

Membership continues to grow. This year our membership exceeded 6000 members (1550 of those members have CP). It is also positive to see an increasing number of members making use of the multi-year membership.

Steptember has been a fantastic success this year- with over 11,000 people participating and raising over $740,000 which will assist us providing you with more support and programmes. Special thanks to Shelly Reilly who has developed the New Zealand aspect of this service and has increased participation remarkably.

Fundraising is a new aspect for our Society. We need to raise funds so we can maintain and grow the assets we have. We have employed some new fabulous fundraisers who are making significant inputs into our corporate's grant funding as well as our marketing and IT. We have been fortunate to employ Bronwyn Gibson, Martin Pepperell and Sarah Rodgers who work alongside Shelly in fundraising.

Research. We are very fortunate to have Amy Hogan working for us managing our research component. As well as a very important research strategy around life-long membership strategy feedback, Amy is chairing the Members' Research group and managing the Researchers' Day which we have agreed to hold annually.

Events. Our Events in Auckland and Christchurch are organised and run by members from those areas. A big thank you to both Events committees as they seek out a range of different and exciting opportunities for our members in their areas. We have also held events in a number of towns and cities throughout the country and will continue to do so next year. We had several lovely fairies' and pirates' parties which we will also continue next year. Very successful coffee clubs are being held by members throughout the country- many thanks to the members who hold them every month. Special thanks to Michael and Kathy who manage our most successful one in Christchurch and have done for many years.

The Dreams Programme has come into operation with young and older members writing their "Dreams". The first random drawer of dreams have been running the rugby ball onto a Test match and meeting the All Blacks; being a zookeeper; having cool wheelchair spokes and attending a Cold Play concert. We will continue to pick the Dreams at random, so please keep sending them in.

Unsung Heroes was drawn this World CP Day with a number of Heroes being randomly selected by Minister Peseta Sam Lotu Iiga. The Unsung Heroes concept is focused on identifying people in members' lives who make a big difference for them. The stories we received were motivational and inspiring.

Last year when we surveyed members and asked what areas we should focus on for improvements, a number of members came back and said both young people and families with newly diagnosed children. These have been priority projects this year, and both will continue to remain a priority for the next few years.

Young People - are being involved in Advocacy training; social events; youth advisory and development projects and Internships. We also have a large project working on improving solutions for Respite for young people.

Families - with Newly Diagnosed Children we are working with a series of partners about how to improve the gaps in support for families around the time of diagnosis. We will keep you informed as we progress.

Advocacy- we have a series of initiatives developing around Advocacy. We are working with the Ministries; like-minded providers and services and also developing skills of young people through training.

Office - I would also like to recognise and sincerely thank the other staff who keep the office, key services, programmes and ideas running smoothly. Special thank you to Michael, Matt, Paul, Travis, Elliot, Grace, Jordon and Ross. Thank you all for your tireless dedication and commitment to the Cerebral Palsy Society - we really appreciate it.

Our Very Own Paralympians

New Zealanders were captivated by the recent Paralympic Games, especially as our team clocked up more medals than ever before. While the news media focused on the high-profile athletes such as Sophie Pascoe and Liam Malone, you may not have realised that two members of the CP Society were among the medallists.

Jess Hamill

26-year-old Jess Hamill who lives in Dunedin with her fiancé Dale (he proposed two weeks before she left for Rio), won a bronze medal in the Women's Shot Put F34. Jess says she was "very happy" with her win. She has been competing in the shot put since the age of 15 when she was a student at Verdon College in Invercargill. She had earlier been a swimmer, but after having some ear problems was looking for a new sport. Jess quickly found she had a real aptitude for shot put and before long was taking part in competitions. She spends 1-2 hours per day training, as well as working full-time as a file clerk for NZ Police, so life is busy for her.

Jess says that, apart from winning a medal, being a part of the NZ team was a real highlight. "They were a great team; we had lots of laughs," she says. "It was such a special experience". After competing, Jess had the opportunity to go sight-seeing around the city of Rio de Janiero. She says she felt proud wearing the New Zealand uniform and being identified as a member of the team. Jess has taken pleasure in proving wrong people who doubted she would find success in her sport. Athletes such as Valerie Adams have been an inspiration to her.

Jess has more competitions ahead, including the IPC Athletics World Championships in London in July 2017. It will be her first visit to the United Kingdom, so she's really looking forward to it.

William Stedman

William Stedman is just 16 but already is a Paralympic medallist with two bronze medals under his belt, winning them in 400 metres and 800 metres track events for his class (level of disability) T36. He also competed in the long-jump, where he came 5th. Not bad for someone who only started competitive athletics in late 2014!

William has always loved sport,

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playing rugby and cricket since he was five, but it was a family trip to London in 2012, while the Paralympics were on there that whetted his interest. He is mildly affected with CP, which mainly affects his left side, and it was only when he saw people with a similar level of disability competing, that he realised he might be able to compete at an international level too. Returning to New Zealand, he contacted Paralympics New Zealand and attended some development camps and “got into the system” and was nationally qualified by late 2014. Attending a “meet” in Brisbane in 2015 resulted in his international qualification to compete and William was on his way to Rio!

William trains at least six days a week, including sprints, gym, jump, speed and endurance sessions and swimming. Saturdays in summer are competition days, while in winter he often does beach-running. Sunday is his well-earned day off. On top of all that, he’s in his first NCEA year at Middleton Grange School in Christchurch. Fortunately, he likes to be busy!

Describing being at the Paralympics as “a pretty incredible experience”, William was impressed by the huge size of the village (especially the massive food hall!), the melting pot of cultures, people from so many different countries and the array of different disabilities represented. He said the Rio locals, more of whom filled the stands than had at the Olympics, were so enthusiastic - and loud! - that stepping up to the podium to receive his medals was “pretty amazing”.

William makes the point that behind the scenes there is a big team of people - his coach, gym trainer, nutritionist, sports psychologist, physio and his family who all play their part in contributing to his success. Having met him, though, I’m sure they would say it was a pleasure assisting such a dedicated and motivated young man.

Like Jess, William is now looking forward to the IPC Athletics World Championships next July in London and, beyond that, to competing at the next Paralympics in Tokyo, Japan, in 2020. His advice to anyone motivated to following in his footsteps is to work hard, don’t give up and use your disability to show what you can do, rather than what you can’t.

We wish Jess and William every success in their future events, and they certainly show the world that having a disability like cerebral palsy doesn’t limit achievement.

Allison Franklin

Photos are courtesy of Getty Images

Living Your Dream

You may remember a postcard in with your May Review. The postcard reads “Living Your Dream”. We asked you to write about a dream you have – something you would really like to do. So we received your responses in the post and these are some of the first randomly select a dreams that came true ....so far!!.

Benjiro Fenwick, his dad Mike, Mum Emma Tamura, and big brother Sam attended the famous All Blacks Captain’s Run,

They had access to the field, and also met some of the players. Benjiro was all smiles and said that “This was the best thing ever.”

Lee Rutene also got to attend the Wellington Lions captain’s run. He received a Wellington Lions jersey.

Levi Shearer, and his family arrived early to get the in the best position to see the action at the All Blacks Captain’s run. They saw training drills, ball passes, high kicks but Levi’s favorite was the Haka. “I got an All Blacks training jersey with 12 autographs, including captain Kieran Read, so it was a good day”, he said.

Our Second Steptember Is Done And Dusted


Maddie, Kyla, Ben hang out with Stan Walker

Not only did we do twice as well as last year, we also walked twice as far with the total number of steps taken being 2,457,779,974 = 1,861,954 km. Which is more kilometres than walking from Auckland to London twice!

We are enormously proud of the New Zealand community for helping to raise over $745,000. We thank all participants, including many members, who took time out of their lives to ask for donations and run fundraising events. 11000 Kiwis signed up to challenge themselves to take 10,000 steps a day. You may have spotted people out walking wearing their Steptember pedometers. We were overwhelmed with the response from the NZ public, with 3069 teams participating.

Much of the success is thanks also to a few helpers we had along the way, including Lee-Anne Wann who came back for our second year after supporting us in 2015. She was joined by the talented Stan Walker who supported the campaign by helping to promote Steptember across New Zealand.


Lee-Anne Wann & Stan Walker

Our five young Steptember ambassadors that the New Zealand public fell in love with and deserve a huge thanks are Kyla, Ben, Bentley, Maddie and Phoenix along with all the families who supported the campaign and helped to create some memorable moments that we have shared in videos and photos.

Many participants have commented about how great they feel after taking part in Steptember, so look out 2017 we will be back bigger and better. It would be great to have more members join us in 2017 to take part and spread the word. Amy Hogan has investigated the ways everyone can join in and make their steps count so please check out her article on page 9. Steptember fundraising dollars will go towards supporting programmes for members, along with the development of new programmes.

Shelly Reilly

National Manager Steptember

Steptember For Everyone

As you are no doubt aware, September was our major fundraising initiative, whether you participated, read our numerous updates or simply heard people complaining about losing their pedometers in weird and wonderful places. The toilet seemed to be a popular location. Steptember was a fantastic success and exceeded all our expectations, both in the money raised and the sense of community that this month-long event fostered.

I wanted to report on my experiences of Steptember as a wheelchair user. As is fairly self-evident, 10,000 steps a day and reduced mobility do not make the easiest of bedfellows. We have been rightly criticised for a perceived lack of accessibility. We are always working to improve fundraising and our services in general. However, I wanted to tell you how I utilised and benefitted from Steptember without taking a single step.

The first aspect I undertook was to source a pedometer that could be affixed to my wheelchair. In the end, and after a long, fruitless search in the conventional places (fitness stores, Fitbit head courters, Smart watch Central) I ended up using a simple bike odometer that attached to my wheelchair spokes and the pedometer unit rested against my chair bars, With some calculations, I was able to measure each of my rotations and their equivalent steps. Let me tell you; I got highly competitive with myself, let alone with my team.

Interestingly, though, I found the equivalent activities measure to be more useful. On the Steptember page, there was a list of about 65 activities that you could choose from, and they would convert the activity into equivalent steps. There were ones specifically designed for CP such as wheelchair sports, Physical Therapy, treatments, manual wheelchair pushing and adaptive movement training.

In future Steptember fundraisers, I would like to promote and assist more people in wheelchairs of any form of reduced mobility to participate. There are mechanisms to be actively engaged in this fitness challenge whatever your chosen mode of ability. If you would like any further information, please do not hesitate to contact me at the following details.

Amy Hogan

The CP Society Website

Remember to visit our website regularly

Keep up with the latest News and Notices

www.cerebralpalsy.org.nz

Notes From Overseas

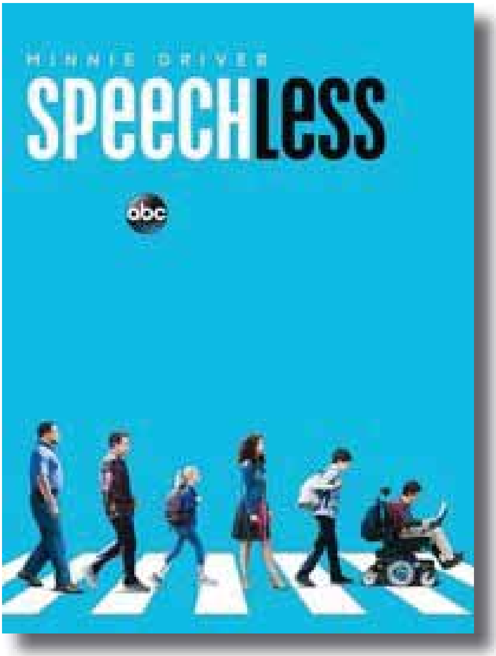
Recently I had the privilege of going to the US to present some of my work at the American Academy of Cerebral Palsy and Developmental Medicine AGM. At the conference there were a great number of interesting speakers presenting on many topics.

A social running program has been set up at Cincinnati Children's Hospital and runners trained as a group in a park for a 5km fun run. The organisers, physical therapist Jenny Angeli and physician Jilda Vargus-Adams, reported many social benefits for the runners. The program, which gained some media attention in the US, is based on running for a set amount of time rather than distance. However, running is not for everyone, I spoke to parent at the conference who was concerned about the fatigue aspects of a running program as well as the time commitment.

During the conference, a new TV sitcom started screening on ABC in the US. It's called Speechless and is by one of the producers of 'Friends'. It's about a family moving to a new school, and one of the kids has CP. I'm not sure how to watch it in NZ, but the trailer on youtube looks good, and it has good reviews online.

Author, Donna Thomson talked about her book about being a caregiver; The Four Walls of My Freedom. Blogger Michele Shusterman also talked about her website, cpdailyliving.com, which aims to be a practical resource. As well as authors, there were also many medical talks.

Dr Christine Roman gave a talk about cortical visual impairment (CVI). CVI does not stop people from perceiving light, but it makes it very difficult to interpret what you are seeing. Apparently, it is a bit like looking at an abstract painting. Reportedly it is very common but not well understood.



Lastly, transcranial magnetic stimulation was discussed by a panel as a possible future intervention. It has promising potential, but its effects and practicalities are not yet well understood. For example, people don't know which areas of the brain should be targeted, at what dose, and how often.

Alex Payne

Alex is a PhD student at the University of Auckland who has been doing research into CP, movement planning, and computer accessibility with the help of some people from the CP Society.

Hon. Sam Lotu-Iiga's Visit To The CP Office

On 21 October 2016, The National Hon. MP for Maungakekie, and in the role of Associate Minister for Health, Sam Lotu-Iigu (and his Senior MP Support, Darrell Stretch) visited our office in Royal Oak to discuss what The Cerebral Palsy Society of New Zealand has done recently (Steptember and the World CP Day), what it plans to do in the future and how the current government might assist the Society.

Each staff member in the office reported and explained to Mr Lotu-Iiga what they were doing in their respective roles in the Cerebral Palsy Society and what they plan to do in the future. Additionally, the interns who were there also contributed. The MP listened with interest and learnt some things about the Cerebral Palsy Society and all the people involved with it.

We had food as we talked with the MP and the staff said our efforts with the voucher/support programmes and our fundraising during September and World CP Day were successes during this financial year (and the last) and the MP was impressed with what he heard.

Mr Lotu-Iiga drew and read out the winners of the Unsung Heroes Awards which are as follows:

Congratulations to our Unsung Heroes!

- Kerrie O' Hara, nominated by Ally and Mike.
- Jocelyn Strange, nominated by Angela Shardlow.
- Max Cole, nominated by Barb and Walter Cole.
- Nicola Clark, nominated by Savannah Clark.
- Shaunaye, nominated by Sharkaela Paora.
- Louis Crawford, nominated by Frieda Crawford.
- Craig Hansen, nominated by Sarah Hansen.

The awards and discussions concluded and then Mr Lotu-Iiga was presented with a painting of flowers in a vase (which is similar to Vincent van Gogh in style) by a member, Lizzie Collenette as thanks for his visit.

Celebrating Our

This year we marked World Cerebral Palsy Day with our first Unsung Hero Award. We had a wonderful response and had to edit the entries to fit in all the amazing people you nominated as your hero(es)- to read the full unedited entries; please go to www.cerebralpalsy.co.nz.

And a heartfelt thank you to all our heroes

Ceri Wackrow's Unsung Hero is ***Carol Keikebosch*** - I have never met anyone who goes above and beyond the way Carol does.

Taima Cameron Unsung Hero is my mum ***Kiritahanga Cameron*** - I don't know how I would cope had I not had my mum by my side.

Barb and Walter Cole Unsung hero is their son ***Max Cole,*** - He has cerebral palsy and works full time helping others.

Ally and Mike Fulcher's Unsung Hero is ***Kerrie O'Hara*** - We talk about "enabling good lives" - that's what Kerrie has devoted her life's work to.

Theresa Maihi's Unsung Hero is ***Joanne Maih***i - My youngest sister is a god-send, and I'm so lucky to have her as part of my life.

Louise and Brysha's Unsung Hero is ***Lillian Jarrett*** - Lillian is the most wonderful person and the fiercest advocate for our families and loved ones who live with special needs.

Sharkaela Paora's unsung hero is ***Shaunaye*** - My little sister is my hero; She is awesome; I appreciate her more than she will ever know. Go Shaunaye!

Kerry and Stella Williams Unsung Hero is ***Karen Williams*** - Karen offers never ending support to families in our area with children who have CP and special needs.

Chad Campbell 's Unsung Hero is my brother ***Max*** - Max is my inspiration, motivator, mentor, friend and brother and when I need extra support through tough times, he is always there for me 100%.

Megan Hayward's Unsung Hero is Janet - ***Janet*** works at Oaklynn School and goes well above the call of duty for the children in her class and their families.

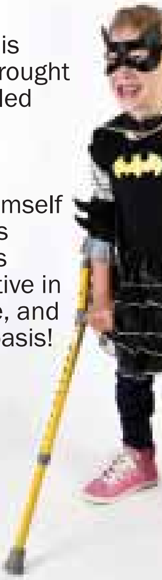
Brodie Johnston's Unsung Hero is ***Bruce Johnston*** - I nominate Dad for the hero day.

Zachariah Hardy's Unsung Hero is ***Clare McDonell*** - she definitely helps me getting around the school which is very tricky she always makes sure I am ok.

Patricia McQueen's Unsung Hero is ***Catherine Chappell*** - She has brought the love of dance to a lot of disabled people including myself.

Frieda Crawford's Unsung Hero is ***Louis Crawford*** - Louis drives himself to school in his wheelchair, makes his own lunch, deals with all of his school correspondence, is pro-active in completing his homework on time, and even makes dinner on a regular basis! He could say 'why me'? Instead, he just gets on with things and participates fully in his life. I am very proud of Louis.

Christopher Dreyer's Unsung Heroes are ***my family*** - I don't know what I would have done without them.



Unsung Heroes

Mandy Slade's Unsung Hero is my mum ***Lyn Slade*** - She has arthritis and even when she has a cold she is still looking after me.

Gemma Overton's unsung hero is her daughter ***Maddy*** - She is our little ray of sunshine and always has a smile and kind word for her family, friends, teachers and physiotherapists.

Savanah Clark's is 5 years old and her hero is my mummy ***Nicola Clark*** - She takes me swimming, and to riding my horse at RDA.

Ocean Daniel's Unsung Heroes are ***Gwen and Ruby Lyon*** - for their amazing friendship, tertiary support, help with auditions and all my Performing Arts endeavours',

Moana Carrol's Unsung Hero is ***my Dad Frank***, - My dad goes the extra mile for me just to put a smile on my face every day.

Olwyn Ferguson's Unsung Hero is ***Sarah Kerr*** - she has got cerebral palsy, but that doesn't stop her from doing things like being a Guide leader.

My name is Troy Robertson, and my Unsung Hero is my ***Dad***.

My name is Liam Melvin my Aunty ***Megan Melvin*** is my hero! - when she found I was deaf she went to learn NZSL she is now fluent in it.

My name is Angela Shardlow My unsung hero is ***Jocelyn Strange***.

Lisa Gill's unsung hero is her son ***Ethan Gill*** - He inspires me and everyone he is around.

Reece Melville from Tauranga nominating ***Brad Emmett*** at Switched On Gym, Tauranga. - He is my go to exercise guy.

Kurt Peterson's unsung hero is my mum, ***Lynn James.*** - I truly would not be the man I am today with all her help. thanks, Mum.

3 year old, ***Jack Eagles' Nana and Grandpop*** (Terry and Anna Rodgers) are his Unsung Hero's. - My Grandparents saw that we were struggling and so gave up their jobs and moved up from Nelson to help us out

Zidane Watts, 8-years-old - My dad's legs don't work, but he supports me in everything I do. ***My dad is an awesome unsung hero*** and I love him so much. He is the best dad in the world!!!

Our support worker ***Tana*** is our unsung hero - Jarrod Braithwaite and his family would like to nominate Tana, We feel really blessed to have found her for our family.

I would like to nominate my Husband ***Craig Hansen***. - he has proven to be my hero in more ways than one, I love you Craig Hansen you will always be my Unsung Hero!! Catheter Man!!

Oakley's unsung hero is his big brother ***Nixon*** - Ever since I was born my big brother has been my hero he is nearly 6 and he is a legend, he has taught me so much,

Bridget McLaren's unsung hero is ***Kathy Thomas*** - She helped me obtain my NZQA qualifications.Thank you very much, Kathy.

Amy's Research Update

As this is the final Review for the year, I thought I would take the opportunity to update you on the research project itself and to thank the participants who are giving their time so generously.

The primary focus of the research is to analyse the data into a workable format so that our members will eventually have access to the information in a meaningful and relevant way. In practice, this has means that I have been collating all of my interviews in various formats and putting all the information into databases. While this is far from the most exciting aspect of my job, I have really enjoyed watching all the experiences of the Cerebral Palsy Society membership come together to form a greater understanding of living with CP through the lifespan. I will have this project completed by the Christmas break 2016.

The goal of the CP through the Lifespan Research has always been to make the data as accessible as possible for individuals with CP and their families. One of the biggest complaints we hear about research is that it is not relevant to an individual's level or type of CP. This is because CP is and always will be, a galaxy of symptoms with as many variations as there are people with the diagnosis.

In order to improve this, I am going to separate the data by topics of interest, level of CP and age brackets. The idea is that people will be able to identify their own circumstances and have the ability to have some reference point for the future living with this life-long condition. There will be an interim membership database ready for review by members mid-2017.

Key research highlights to date include:

- Age range between 17-79
- All levels of CP represented

- Interviews conducted in most areas of New Zealand including all major cities
- Profiles developed of mild, moderate and severe CP
- Profiles developed of some of the most common complications of CP such as speech difficulties, pain and fatigue
- Development of strategies around everyday events in adulthood such as leaving school or entering the workforce.

As I have said in previous articles, I am always looking for more participants as this is an ongoing project and looks to gather as much information as possible. Goals for the next intake include developing a questionnaire for parents of children with CP. Further we will develop an interview system that is tailored for people with level 5 CP who use augmented communication devices that limit face-to-face and online formats.

If you are interested in contributing to this work or have further questions, please contact me at amy@cpsociety.org.nz

Research Opportunity

Do you live in Auckland, Canterbury, Wellington, Waikato, Bay of Plenty or Otago?

Do you have a disability? And are you over 18 years of age?

Or do you care and support (paid or unpaid) for somebody with a disability?

Have you travelled together (domestically and/or internationally) during the last year?

If you answered 'YES' to all of these questions, you have a unique opportunity to have your say!

Brielle Gillovic, a PhD student at the University of Waikato, wants to hear your stories and has asked us to distribute this message to you. We invite you to participate in this research so that together we can improve the care experience for others who travel.

Please feel free to pass this message on, if you know of someone else who can answer 'YES' to the questions above.

If you are interested in being a part of this study, please contact Brielle at bsg6@students.waikato.ac.nz or on 027 3919 020

Consumer Report From The Consortium

I have two children, my youngest Tyler is a member of CP Society.

I have just attended my second meeting as a parent representative at the Consumer Consortium in Wellington. The Consortium was developed to represent service users/consumers from a wide range of disability organisations who use Disability Support Services. It is capped at 28 people, 67% are people with disabilities in the group.

What the Ministry does?

Spoke about where does disability fit into service commissioning, making sure the system works, think about people they work for and working together. Outlined the broader view of MoH work and their structures.

Respite Strategy

The Ministry of Health is writing a respite strategy to improve the way we purchase planned respite or "short breaks" for carers of a person with a disability.

They have put some information about the strategy and a link to a survey for disabled people and their whānau on the Ministry of Health website: www.health.govt.nz/our-work/disability-services/disability-projects/respite-strategy-2016-17

The "MOH Respite Survey for families" is designed to be completed by the person with disabilities or on their behalf. It will be open until the 30th of November 2016.

Enabling Good Lives (EGL) Christchurch Evaluation

The evaluation was based on "Quality of Life" questionnaire with eight domains and three broad areas: independence, self-participation and well-being. The presenters acknowledged that there were limitations and improvements could have been made in the right domains such as: socialisation/inclusion, choices, financial status, and that parents had high expectations for their young people leaving school.

Update for EGL Christchurch:

The process was designed around school leavers with 247 opting in. 41% female, 59%male; 37% Very High Needs, 57% High Needs, 6% unknown. There are 42 school leavers at the end of 2016.

The pilot has now finished with one person taking over the role. 11 Flexible Disability Support Agencies are now contracted to provide the service.

EGL Waikato Update:

The EGL principles were the same but were driven differently. This lead to big improvements and positive effects to people's lives.

The statistics for complex/high needs is around 30%. Maori account for a high percent at 32%, 7% Asian, 5% Pacific Island, 6% NZ/European. Half were adults, children and very young children.

My feedback on EGL/Christchurch & EGL/Waikato

These two sessions were of interest to me as Tyler, and I were one of the first families to opt into EGL-Christchurch.

The difference between the two is Waikato were able to manage their own funding. They could choose who supported this such as the local iwi. Christchurch was not given a choice and used Individualised Funding. They had a better understanding of complexities of the people, the situations and this would have made a difference to Christchurch families.

Service user feedback on MoH funded residential disability services

This was a report by Malatest International for the MoH on clients using

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Residential Services. The responses are from 356 people (322 face to face, 35 proxy). This covered two areas in Auckland, one in Wellington and one in Manawatu. The results were high using the Quality of Life questions for satisfaction with where they liked to live, had a choice of where they lived, had enough staff and the right staff.

DSS Prevention of Abuse Guidelines.

This document “The Prevention and Management of Abuse: Guidance for Safeguarding in Services Funded by Disability Support Services” is for providers with a core focus is on Residential Care.

It is about to be published on their website.

Community Residential Living Strategy:

DSS are allocated for various services based on historical trends.

Residential is growing not so much in numbers but more so in needs requiring more support. Equipment costs are growing due to ageing population. More people are being supported to live in the community.

The team are working on a range of strategies to create and encourage development of creative, flexible and effective solutions for greater choice, control and flexibility

DIAS/NASC Review (DSS Disability Information and Advisory Services (DIAS)/ Needs Assessment and Service Coordination (NASC)

A survey was conducted with individuals, groups of providers and consumers as well as an electronic survey from 107 providers, and the outcome presented a significant challenge to MoH and all recognised the need for change.

DIAS & NASC are all doing things differently, demands are increasing. DIAS and NASC need to be the same, some NASC doesn’t know DIAS and the systems now are fragmented, knowledge is not shared. The findings will be published on the website in the next five weeks.

Whàia Te Ao Màrama:

This session was the about the process and contract feedback to the group.

A very low number of Maori with disabilities access Disability Support Services. This raises the question how do you improve outcomes for Màori and what are the barriers? In my opinion, the consortium felt they could not make recommendations as this is not their field of expertise.

Community Rehabilitation strategy.

This presentation applies to those who are affected by stroke or brain injury. Residential Rehabilitation is only available in Northland, Auckland, Waikato, Hawkes Bay, Palmerston North, Wellington, and Christchurch. Non-residential Rehabilitation is available in Northland, Auckland, Waikato, and Christchurch.

NZ Sign Language

Plan for 2016/18 was outlined. Only one action of 13 is led by the MoH. A survey will be undertaken by NZ Sign Language for parents of deaf children, and consortium members will be asked to send the link out to relevant parties.

Low Vision

The Low Vision Rehabilitation Services Strategic Direction was developed as a crossover with DHB Community Eye Health and Private Eye Health. The service is directed towards the older age group as there is a significant increase in ageing population with a common diagnosis: diabetes, glaucoma, optic nerve damage, etc.

Andrea Lamont, Christchurch

Call For Interns

We are again offering an internship which is a fixed term structured unpaid work experience programme which can be related to your area of interest. Internships give you an opportunity to work in the working environment, demonstrate your work ethic and provide you with an excellent opportunity to enhance your recruitment activities through improving your CV and good references. There is NO commitment for on-going employment.

Mostly we are looking for interns who are members with Cerebral Palsy and are excited to learn new skills with a good work ethic. We would also like interns to have some of the following skills- good writing skills; research abilities; good formatting and editing.

We are looking for one or more interns to undertake work for us in the following areas:

- Membership research
- Research
- Administration
- Fund raising and marketing
- Management.

Timeframes and hours are negotiable.

If you are interested, please send your CV or write in person to: gilli@cpsociety.org.nz

Turtle Steps Win The Race

Grace Eunhye Hwang has a BA from AUT in Japanese and speaks three languages Korean, Japanese and English but after she had graduated things did not go as planned.

‘I was very despondent after I finished studying and found I stopped venturing out from home. I had no plans or direction, but my brother and mother really supported me and encouraged me to keep going. When I saw the advertisement for the intern programme in the review, they really encouraged me to apply, and my brother even accompanied me to my interview for the internship.

Grace, despite her obvious nerves at the interview was accepted into the internship programme along with two other applicants. ‘I can’t believe how far I have come, I was so frightened when I came in for the interview, I did not believe I could do it. Grace has also found that her personal development has gone from strength to strength.

‘I felt worried about how I would cope before I started and would get headaches just thinking about going to work or driving’. But now Grace has pushed through her fears and achieved both these things. ‘My confidence has shot up. CP has not been a problem within my workplace; any problems faced have been overcome; like the printers that used to drive me crazy.

‘I think I made lots of mistakes in my first weeks’ said Grace, however, everyone in the Cerebral Palsy Society Royal Oak office was so supportive throughout her placement. ‘They have been so committed to my personal development allowing me to gain skills in as many roles as possible and helped me begin to understand how a team works to make things happen in an office.’

‘The CPS Intern Programme started the development of my confidence, and I feel this programme has now pushed it to where it should be.’ Grace would recommend internships to others and has found that it has been a great experience. ‘I would describe the intern programme itself as life changing, not only has it developed my professional skills and how I cope with my CP within a workplace, it also allowed me to meet others who face the same struggles as I do.’

As they say in Korea you just need to start by taking “turtle steps”.

Her new-found confidence helped Grace apply and win a much-coveted 6-month placement as an admin assistant in the CBD at the Be. Employed Internship Programme for new graduates to gain work experience.

This placement is coming to an end, so Grace is now out there on the job market with a wealth of experience and confidence. So if you are looking for an admin assistant in the CBD Auckland, Albany or North Shore get in touch.

The Turtle: The turtle approaches change in baby steps. They think for a long time about the change they want to make. Once they decide, they inch along, take a rest now and then and eventually arrive at the finish line. If the change comes too fast, look out! They will pull their head inside their shell and won’t come out until it feels safe.

It Is Not Just About Cars

Alister Brunsden

When Alister Brunsden purchased Vehicle Adaptions Ltd in August 2015, he had no idea how much his broad range of knowledge and mechanical background would come in handy, not only for helping people with CP to get behind the wheel, but one day also solving a hair emergency.

Alister was looking for a business that had a heart when he became the new owner of Vehicle Adaptions Ltd, experts in the modification of vehicles for disabled drivers, where they take great pride in providing a high quality of service. From wheelchair hoists and hand controls to custom vehicle upgrades and modifications, they have the industry experience and knowledge to get you successfully on the road.

Usually, Alister uses his experience in process controls, automation and electrical engineering to modify vehicles for disabled drivers, but after a call for help from Parkwood Hospital, he turned his problem-solving skills to modifying a hair washing tray for our CP Society Member, Rachel Mullins.

As inventive as Alister is, he found keeping an open mind was essential as the conversion went through many iterations until he had that eureka moment. Though it has taken several months to finally find the right solution it was worth it “I am happy with the result “said Alister.

It was very much trial and error with many aspects of the hair washing tray being an unknown area. I had to research extensively with multiple salon visits and hours of research, I have become quite an expert now, stated Alister.

And the result! One very happy client who is very grateful to be able to now do what many of us take for granted. Thank you from the bottom of hearts, Alister. you are awesome.

Paul's Vintage Mowers

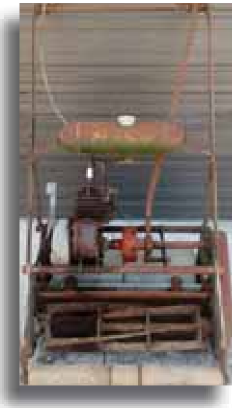
Our CP Review Design and Webmaster, Paul Munckhof, is a man of many talents. The least known of these talents is his ability to buy worn out, vintage lawn mowers off Trade Me and restore them back to their glory days. If new parts are needed, with a bit of hunting around eBay, most parts can be found.


Before After

A 1966 Masport with a 2 stroke Iron Horse engine is his latest completed project. When Paul brought the Masport home he had to completely dissemble it as it was clogged up with dirt, due to many years' of neglect.

The next step in restoration was repainting it in original colours before it was reassembled. This included reinstating the decals with help via the computer. Details and an instruction guide were carefully put in their proper places on the engine cover. Re-chroming the mower's handle was the final touch

The next project, a 1950's English Atco reel mower with a 2 stroke Villiers engine, is already on the garage bench.


The new project

Encouraged by his old man and a staff worker at CCS, Paul has always had an interest in fixing small engines. As a teenager he scooted round the neighbourhood in a go kart and naturally enough this lead to an interest in dabbling with the kart's Villiers engine when things spluttered to a standstill. He was given great confidence when the engine sprung to life again due to his developing mechanic skills.

Paul regards his interest in mower restoration as a hobby rather than a job but would love to see his projects displayed in an appropriate museum one day.

Although his main focus is on lawn mowers now, in the past he has had success at fixing other small engine machinery such as chainsaws and weedeaters. He can also find his way around the internal workings of a computer.

A talented man indeed, is Paul.

Ross Flood


Iron Horse Carburetor
Before After

Academic Grants 2017

The Society's academic grants are now open for members to apply. The maximum grant value is $2500. The applicant must be studying for a Bachelors degree or higher and have passed a successful year at this level.

The grant can be used for course fees, student association fees, travel to or from University and text books or course materials. It cannot be used to pay off a student loan.

Applications are now open and close on the 20th of January 2017. You can find the application form under grants on www.cerebralpalsy.org.nz

The Cerebral Palsy Society's
Holiday Boccia Tournament
21st – 22nd January 2017
Allan Brewster Leisure Centre
Tavern Lane, Papatoetoe

The competition this year will be a PAIRS tournament where you will be assigned a partner. Also your pairing will be assigned a handicap rating in order to even out all the pairings. Handicaps may be altered after the pool rounds. A maximum of 32 pairs (i.e. 64 players) will be accepted on a first come-first served basis.

This Tournament is designed to have fun and get new people playing the exciting game of Boccia. We encourage new players to take the plunge in a very friendly environment. You will be partnered with someone who will guide you through your games, so sign up. Lunch will be provided both days, and there are great prizes. Any queries please call Michael on 0800 503 603 or Scott on 021 0205 9911. Note: If you need assistance during the day for personal care or assistance with eating lunch, you must organise that support prior to the tournament. Asking someone on the day is not an option.

Any queries, email: cpsociety@cpsociety.org.nz or boccia@boccia.org.nz

ENTRIES MUST BE RECEIVED NO LATER THAN

Friday 13th JANUARY 2017

TA Powerchairs 100% Safer*

You may not be aware but not all powerchairs are created equal when it comes to your safety.

Most powerchairs* available in New Zealand are not safety crash tested. That is they are not certified and proven for you to remain safely seated in your powerchair when being transported in a vehicle.
You may not be as safe as an able bodied person in a standard vehicle seat.

If you had a choice when buying a new car would you accept a vehicle without a 5 Star ANCAP rating ?
We don't think that this is acceptable. All TA Powerchairs are crash tested for your safety and confidence.

The ISO standard 7176-19:2008 measures a powerchair with an occupant seated in their chair within a vehicle in a simulated 50kph impact using a hybrid dummy of 77kg. With an average powerchair this equals a stationary mass of 220kg, at impact this increases to 3500kg. The dummy and all powerchair components are then measured for movement, stress and damage.
It is a pass or fail when it comes to your safety. No different to simulated crash tests for an occupant in a car or van. To view crash test videos for TA powerchairs scan the QR code below or visit our website.

It is that simple, ISO crash test compliance for powerchairs is now the norm in European markets.
To be confident you are the safest you can be, there is only one question you need to ask:

Has your powerchair been tested and approved to ISO 7176-19:2008 ?

You do have a choice - TA the New Standard

Sit lower under
tables and desks.

Scan the QR codes for videos

Crash Test
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Crash Test
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12.5kph/40km.

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