

The Review

Official Magazine of the Cerebral Palsy Society

July 2018



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Cerebral Palsy Society
freedom & choice

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Tenacious Poem

Hamish is an 18 year old with cerebral palsy. He would like to thank the Cerebral Palsy Society for the opportunity to have an experience of a life time. Hamish struggles with anxiety and lacks confidence in himself.

We encourage him to be involved in positive activities which are most

successful when he is surrounded by patient, empathetic and encouraging people. Tenacious Tall ship experience had it all, adventure, an encouraging environment and awesome people. Hamish was able to meet some of the crew prior to the journey which allowed him to get to know others and feel more comfortable about his six-night adventure from Auckland to Great Barrier Island and back down to Waiheke Island.



The following poem was written on board by Hamish and I Mel, Hamish's mother along with some input from The Port Aft Watch

Tenacious

You are accommodatingly spacious
We are learning to go with the flow
Even though we may be a bit slow
Captain Darren and first mate Fliss
You help make the journey bliss

From Great Barrier, down to
Waiheke, over to Rakino And back
down to The City of Sails Tamaki Ma
Kaurau

Tenacious

You are incredibly courageous
We ease and we haul
We climb and we don't fall
You sail with ease
In the Waitemata breeze
Is it the bunt line? I haven't got a
clue
Some of us were queasy
And a little bit sneezy.

Tenacious

You are so gracious

It's about building character, living
in the moment, respect, support,
encouragement, knowledge,
wisdom, curiosity, positive attitude,
sharing and listening to each
other's narratives.

The 24 hour routine of great food

To keep us in the right mood

Watch... get your bearings

Sailing at the helm

Happy hour and mess duty

Tenacious

It's people, It's people, It's people
He Tangata, He Tangata, He Tangata

Written by The Port Aft Watch

News From Our CEO

I hope you are all keeping warm as winter well and truly sets in.

Firstly, I'd like to acknowledge that we haven't sent out a Review for a few months now. We've had to prioritise moving premises, recruiting new staff and focussing on finalising our strategic plan.

I'm pleased to tell you that all these things are complete and going forwards, we plan to have a more regular schedule in place for sending out The Review, as well as some new ways of keeping in touch.

I am also happy to share with you that we're happily settled into our new offices at 8 Railway St, Newmarket, in Auckland. We have a larger, lighter space and would love members to drop in if you are in the area.

I recently attended our latest Board meeting which was held in Christchurch, followed by a member dinner. At this meeting, the Board signed off our 2018 strategic plan and budget. You will find a copy of the plan on page 6 and 7.

We really value your feedback on all aspects of what we do, and welcome suggestions for ways we can better meet the needs of our members. Attached is a short survey that we invite you to complete on The Review so we can



learn more about how often you would like to receive, in what format you prefer; and, what content you find the most interesting and relevant.

Once you have completed the survey, please return it to us in the postage paid envelope or if easier, scan or take a photo of your survey and email it to us.

All the best

Gilli Sinclair



Update On Innovations

There's been a lot happening at The Society. Below is an update on just some of them:

- We are in the process of reviewing our membership information - please get back to us with any changes in your information - so we can ensure all our information is correct.
- We have made changes to some of the programmes based on your feedback- getPhysical has been operating as an annual programme for the past year. This has worked well for most of our members so we have extended it to getOutThere so people can decide when they would prefer to use their taxi vouchers.
- The office has supported over 200 individuals with advocacy needs
- Cerebral Palsy Society is leading a proposal to funders for an Advocate across the physical disability sector to be based at our office. (This is funding dependent). This style of advocacy will focus on systems not individual's needs.
- The Youth Alliance board is working well promoting "Freedom of Rights" due to be released soon.
- Work is nearly completed on a Pilot for Respite for Auckland for young people in partnership with Geneva. If this is successful, we can use this model to support more opportunities for young people.
- We have held a number of parent perspective meetings including involving Iona Novak (researcher) and Ian Hunter.
- We are close to requesting funds and research proposals around SDR and Intensive therapies.
- We have completed the first phase of the new website
- We have several new staff:
 - Sue Lewis-O'Halloran is the new VP Development and leading our fundraising team.
 - Saraid Black is the new Director of Communication and Marketing.
 - Steph Maitland is contracted to help us apply for all our grants.
 - Gemma Overton is establishing a parent perspective programme.

Winners From The Survey 2018

We are pleased to announce the 5 winners randomly selected from members who participated in our survey. Each winner received a \$50 voucher of their choice.

They are: Jarod McClintonck, Krystal Robertson, Sophie Greenwood, Jess Perkins and Angela Shardlow

Congratulations and thanks to everyone who participated, we appreciate your feedback.

ADVOCACY & VOICE

To amplify the voice of our members we will:

- Share quality information and knowledge for members to enable informed choice
- Become a centre of excellence for CP knowledge in NZ
- Grow youth alliance initiatives for ongoing leadership and advocacy
- Establish and maintain a physical disability consortium to prioritise initiatives and strengthen opportunities for members' employment and youth transitions with a focus on education, health and social interactions
- Maintain regular meetings with councils and ministries to support members' needs
- Re-examine, then grow the concept of CP Day
- Collaborate with organisations to advocate for people with physical disabilities



[cpsocietynz](https://www.facebook.com/cpsocietynz)
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FINANCE

The CPS team will ensure continued viability and sustainability. We will:

- Enhance the growth and development of Steptember
- Support the investment developments of Essential Assets Ltd
- Support the developments of Cerebral Investments Ltd
- Implement a fundraising strategy designed to increase financial capacity



STRATEGIC PLAN 2018

Cerebral Palsy Society
freedom & choice

To change New Zealanders' attitudes to physical disability

DEVELOPMENT & INNOVATION

We will strategise with our members to create innovative solutions as we:

- Design and develop improved options for respite
- Scope SDR opportunities and research-intensive therapy options
- Undertake systematic evaluation of our programmes
- Expand the life span research with a focus on older members and people with CP at levels 4 and 5, including those who are non-verbal
- Work with the Youth Alliance to co-design solutions focused on transitions for young people living with physical disabilities
- Design and develop strategies to improve support for families with a child newly diagnosed with CP. The proposed solutions are based on feedback from our members. They include:
 - Expanding the “consulting group” of parents to other areas
 - Refocusing aspects of the website to enable parents easier access to information
 - Developing an information package for new families



PEOPLE

We will survey our members to understand their needs so we can deliver enhanced services to them.

We will:

- Share information and knowledge with our families
- Strengthen, improve and expand our programmes, including:
 - Grants
 - Events
 - Coffee clubs
 - Dream programmes
 - All of our “Get” Programmes
 - Boccia
- Become the access point for relevant and up-to-date information for the general public
- Through our website, Improve and inspire communication for our members, including new families, and engage our donors and corporate partners
- Develop and implement a volunteers’ programme
- Grow and strengthen our intern programme

To consistently improve our programmes, which will empower our members to enhance their lives, we will:

- Work on representation and inclusion by engaging with members across all ages and levels of CP
- Act as a conduit to network members with peers, services and opportunities



Medical Cannabis Part 2

The Science

The scientific understanding of how medical cannabis works on the body to treat a wide variety of symptoms is the subject of much debate and study. The effectiveness of the mechanisms has been difficult to study.

This is due to the controversial nature of the drug involved.

Interestingly, there is little resemblance between medical cannabis and the recreational drug as the chemical compounds act on different parts of the brain. Medical cannabis does not get you high.

As a consequence of this, evidence of the effectiveness of medical cannabis in treating symptoms has remained largely anecdotal. There has been little study done on the proper and safe dosages and which varieties to use for a given condition. This needs to be established scientifically.

Recently, there has been a series of studies undertaken to scientifically assess the effectiveness of medical cannabis in the conditions that the drug is most frequently used for. These include epilepsy, chronic pain, chemotherapy symptoms and other neurological disorders. Neurologists are particularly interested in undertaking this research because severe epilepsy is one of the conditions that are seeing the highest demand for cannabis interventions. There is considerable public attention around its positive effects on some of the worst cases of epilepsy.

There are four main recent studies that have investigated the effectiveness and safety of medical cannabis. The majority of literature indicates that cannabis does treat these symptoms to a degree, is definitely more effective than the placebo and offers more relief from symptoms than conventional opioids. In the case of epilepsy, there is a reduction in seizures from between 30-50%.





In the pain studies, symptoms were relieved in the majority of cases, and people reported improvements in their quality of life and their ability to function. In a smaller study on cancer patients, it effectively helped them contend with the consequences of being on so many strong medications such as relieving nausea, severe pain and easing their symptoms of digestive disorders. All the studies reported that there were fewer side effects than the conventional medication and they did not need to rely on secondary medication to counter the side effects.

However, it is important to note that patients in this controlled setting were not side-effect free. The hype around medical cannabis often states that there are little to

no side effects and that it naturally integrates with the bodies systems. However, this is not the case. There were individuals for whom the medical cannabis had adverse reactions, and they needed to withdraw from the study. Furthermore, there were people who indicated that the cannabis did not improve their quality of life and they saw no symptom reduction. Therefore, it is important to properly identify the patients that are going to respond well to the medical cannabis and understand the fundamentals of dosage and strands of cannabis.

The takeaway message from the current research as from 2017 is that medical cannabis can be an effective tool for treating severe and life-altering symptoms. However, it is only a tool, not a panacea and shouldn't be treated as something that can be taken without due consideration. If you would like further information or copies of the studies referenced, please feel free to email me. I will be setting up a mailing list at the request of members to inform them of any of the latest research or movement in the government policy. Let me know if you would like to be added.

Amy Hogan

Disability Support Services Consumer Consortium Report



This was my first consortium as representative of the Society. I was very nervous walking into the room which was filled with people from various organisations across the disability sector. I took a seat not knowing what to expect or how I'd cope, but as we worked our way through day one things started to calm down and fall into a steady rhythm.

Over the next couple of days, I met and enjoyed the company of some really cool people and learnt so much about Disability Support Services (DSS) in New Zealand overseen by the Ministry of Health at the consortium. I am now looking forward to the next meeting.

A very productive discussion took place between representatives from various organisations across the country aiming to provide the best possible support for differently-abled individuals. The main themes of the discussion touched on the importance of making daily life more accessible and disability-friendly, including

things such as using public transport, or ensuring better living conditions at home. The consortium also focused on ways to get DSS and the Ministry of Health to be more transparent with differently-

abled individuals. Transparency regarding information, equipment and funding were frequently discussed among many other things. The consortium unanimously agreed differently-abled individuals deserve more freedom and access and that the rights of such individuals need to be better upheld by the New Zealand Government.

Enabling Good Lives, an approach to transforming the Disability Support System was also revisited and discussed amongst everyone at the consortium. It was concluded that differently-abled individuals want better choice and control over their lives, lower costs and improved government funding. A promise to address these concerns was made so hopefully things will improve very soon.

More information about 'Enabling Good Lives' can be found at www.enablinggoodlives.co.nz

Sid Gudipoodi

Vibration Therapy



Karen getting her back treated

Karen O'Leary, a member of the CP Society with diplegia (GMFCS:2), suggested a coffee meet up. Karen always has something interesting on the go so we caught up over a cappuccino.

We brought our lives up to date then Karen proceeded to tell me about her journey doing vibration therapy at Vibra-Train in central Auckland. It was difficult for Karen to contain her enthusiasm for the results achieved since beginning six weeks ago.

Karen had heard of vibration therapy but it took her increasing pain, deteriorating mobility and sagging spirits to make her go. She tried a vibration machine at a reputable supplier but sensed they lacked expertise. A google search led her to Vibra-Train where she found the expertise she required that covered disabilities. The machines there are nothing like those on TV or available from Elite. An experienced instructor is vital. During Karen's first visit the pain fell

away making her realise how much she had been in. On the second visit hips began to come into alignment and each visit saw progress. Her family started noticing physical improvements and improved well being. After 10 visits she was mobile enough to bus in, freeing herself from dependence on friends/family to get her there.

So what has Karen taken on? Each session is around 10-15min of vibration therapy, involving different positions to address different areas of the body. A minimum of two sessions a week is required (Karen goes everyday). The cost is zero if you are disabled! As with everything in life, you get out what you put in, and this is quite a commitment to maintain, but let's face it, pain is a great motivator. Programmes for those in wheelchairs are available.

When I visited Vibra-Train, Lloyd Shaw, the manager said it's great for your back and can improve your golf swing. Hey, all you carers and golfers out there, we could do with giving our backs some TLC right! I'll give it a go and report back in the next issue..... and more details on Karen's continuing journey. Here is a link to Karen's blog on this;

<https://hopeforlivingwell.wordpress.com/>

Harvey Brunt

The long road to HAMILTON



I was sitting in my, up-until-now, faithful van of fourteen years, feeling deflated. The van was packed to the rafters with furniture I was taking down to my new home in Hamilton.

Alas, my journey was cut short at the traffic lights on Puhinui Road which was approximately a block away from where I was living in Papatoetoe. To make things worse, the weather gods were delivering torrential rain. I rang the AA to request a rescue. In the meantime, my fellow passenger and I decided to nurse the van a little further towards home.

I managed to steer the rapidly deteriorating engine around a couple of corners to Cambridge Terrace where my old friend cried enough and flaked

out on the spot, never to spark to life again.

I thought the arrival of the AA man would be the end of my troubles for the evening until he informed me that it was against policy to allow me to stay in the van on the back of the tow truck. Eventually, I managed to point out the folly of this policy which would have involved the unpacking of the whole van and leaving the furniture to be waterlogged on the side of the road and then try to somehow fit myself and my motorized wheelchair into the front of the tow truck cabin. This I'm sure you agree, dear reader is the definition of impossible. I'm pleased to inform one and all that I survived the one-kilometre journey home.

After I thanked my companion, who without hesitation unpacked my belongings in appalling conditions, I sat in my bedroom in a foul mood. I already had the frustration of the family lawyers trying to convince me to have a video conference involving my sister over my choice of place of residence. Being a person of sound mind and rational thinking that suggestion went right up my nose. The idea quickly vanished but the residue implications' remain sour. As my sister aptly put it "Who do they think I am, your mother!!!"

Of course, now I had another problem in the form of no vehicle. Fortunately, I had bought a modified Skoda Yeti and was waiting for its arrival. Well, it did arrive the day before I was scheduled to take ownership of the house but it quickly became obvious that

I couldn't just take command of the steering wheel and take off to Hamilton the next day. I needed practice. I had a dilemma on my hands as I needed to be in Hamilton as I had cancelled my Auckland support people and hired my Waikato staff. The people who I was living with came to my rescue. Angie stuck up her hand to drive me down with her husband Sam and daughter Angel in convoy.

All problems solved or so I thought. I was having problems with hiring support staff via the IF system. Previously I thought everything was in place until the person I hired broke her elbow, (goodness knows how), and I was back to square one.

I hired another who was going to come and see me that night. So I thanked my friends who needed to go back to Auckland to start work the next day. Much to my horror, the new, so-called, support work decided that night that she didn't want the job as it was too far to travel. In a mad panic, I rang Angie and Sam who very generously turned their car around and headed back to Hamilton to save the day.

My support worker woes continued until my former support worker Sheenal, who I now regard as a daughter, came back to me from India. Now she and her husband and my best buddy!!!, Chandan, are now my live-in support workers. Thanks to their help I'm finally well established in my city of choice

Also thanks to dad's last gift to my sister and me, I can continue living independently.

Ross Flood

How Funds Raised From Steptember Have Made A Difference



Because of the more than 17,000 Kiwis who took part in Steptember last year we have been able to fund lots of important programmes and initiatives for our members. Just some of these include:

More than \$110,000 of getPhysical vouchers were sent to members

More than 400 people attended events in 14 cities around NZ

We were able to support members and their families to get nearly \$20,000 in legal support and counselling

We funded more than 50 grants to the value of nearly \$50,000

We held fairy parties for more than 100 children

125 members received getThis&That vouchers

We sent out \$15,000 of getOutThere vouchers to help give our members greater access to the community

We were able to launch the Parent Network to improve services to members to members with children

Funding enabled us to actively engage in ways to shift perceptions of New Zealanders to physical disability through working with others in the sector

New initiatives to improve the way we meet the needs of our members were launched, including working groups looking at respite and the voice of our young people through the Youth Alliance

How Steptember Is Making A Difference

The 2018 Steptember campaign is coming up and we'd love the support of our members to make the most of this important fund and awareness-raising opportunity.

The Board acknowledges that some members have expressed concerns about Steptember and it's important that we address these as well as share with you plans for this years' campaign.

Why we need Steptember:

We want to be able to help more people with cerebral palsy to have greater freedom and choice in their lives through our current programmes and new initiatives. To achieve this, we need new sources of funds, and ideally ones that allow us to also raise awareness of both the Society and people living with CP.

Since it launched in New Zealand in 2015, Steptember has gone from strength to strength, with total revenue more than doubling in just three years. In 2018, we want to see that rise again and have set a target to raise over \$1 million this year. These funds are vital for us to be able to provide our members with the best opportunities to have access to programmes and services that improve and enhance their lives.

How funds raised during Steptember are allocated:

As you are probably aware, the Steptember concept is owned by the Cerebral Palsy Alliance in Australia, which means they receive a fee from us and the other countries that run Steptember campaigns. In return, we receive a tremendous amount of support to ensure we raise as many funds as possible.

A percentage of what we raise also goes to Australia to fund world-leading research by academics such as Professor Iona Novak. We believe, the Society and our members benefit greatly from that research, which is used to help inform the member programmes we run.

What's happening this Steptember and how can you get involved?

In late July, we'll start putting the word out to encourage four-person teams to register for Steptember 2018 and we'd love your help!

Steptember is about encouraging Kiwis to get moving for a good cause. It can be by taking 10,000 steps a day or participating in numerous other physical activities – from swimming and cycling and dancing to pilates, Boccia, wheelchairs transport.

If you, or someone you know, would like to get involved, it would be wonderful to have you join Steptember 2018. Get in touch with us on 0800 503 603 or steptember@cpsociety.org.nz and we can give you all the information you need. Good news is that registration fees are waived for CP Society members if you enter the code MEMBERS when you are completing your form.

We are aiming to sign up more than 20,000 people to take part in this year's Steptember campaign, so hopefully you will see and hear about the campaign through a variety of channels.

We will be posting regular campaign updates to our website the social Steptember media channels (Facebook and Instagram), so be sure to check them out.

If you have any further questions about Steptember or would like to provide us with additional feedback please don't hesitate to get in touch.

TalkingMats

Improving communication, Improving Lives



Recently, I was given the opportunity to complete a foundation course on a new form of augmented communication. This tool is specifically designed to improve the communication opportunities for people who have limited or no verbal communication. A team of Scottish speech-language therapists designed Talking Mats, and it has recently become a global initiative.

Talking Mats is based on a well-established communication framework that has been used by individuals and their families for decades. This tool provides a visual framework for allowing individuals with limited communication to express their opinions on their experiences of daily living. There are a series of cards that depict a broad range of topics. The cards are then placed along a scale from that reflects how the person feels about that particular topic either positively, negatively or neutral.

- First, a topic is selected that is related to the individual's life circumstances.
- A communication board is set up with the topic at the top and the three response cards laid out in a scale from negative to positive.
- The individual is asked to place a

series of cards along the scale. For example, the topic may be mobility, and the questions include "how do you feel about getting in and out of the car, household areas, and walking outside?" The idea is to get a comprehensive picture of how the person is feeling about a particular issue.

- Once the communication board is complete, the person asking the questions asks if there was anything they would like to add using blank cards and the individual is asked if there is any point in the board that they would like to alter or feel particularly strong about.
- The individual asking the questions then takes a photo of all the cards in their different positions. This can be used as a reference point for making changes to the persons care or support. For example, some individuals using this programme have talked about medication difficulties and not understanding their doctors.

The individuals can choose what aspect of their lives they want to talk about. There are a variety of boards and card sets to select from. A wide variety of disciplines utilize the cards. For example, there is a Keeping Safe set that is used by social workers and paediatricians to ask children who are in difficult



situations if they are feeling safe and what frightens them about their current situation.

What I like about the communication system is that it is very adaptable and each of the parts can be adapted to reflect a broad range of ages, circumstances and ability. There is a basic formula to follow, but you can change this as required. The prospect of talking about sensitive, health-related information can be intimidating, particularly if you have a communication disorder.

This programme allows you to provide information at whatever level you are comfortable with. This tool can prompt dialogue about the aspects of life that are most relevant to the person. You can provide the baseline information or the answers to the first questions

can be used as a way to open dialogue. For example, the tool is frequently used by doctors looking to assess how chronically ill adolescents feel about their medication protocol as it is a good outlet without requiring lots of conversation.

I am planning on doing a series of demonstration videos using the set of cards I was given as part of the course. These will reflect common questions for people living with complex Cerebral Palsy. For example, "How would you describe your health currently?"

For more information go to www.talkingmats.com or contact me at amy@cpsociety.org.nz

Amy Hogan

Website Update

The Cerebral Palsy Society website homepage features a banner with the text "The CP register needs you!" and a call to action "Help increase our knowledge of people with Cerebral Palsy in New Zealand". The banner also includes logos for "CP Register" and "Starship". Below the banner, there is a navigation bar with links to About Us, About Cerebral Palsy, Events & Activities, News & Updates, and Support Us. A phone number 0800 503 603 is displayed, along with social media icons for Facebook and Twitter, and a "DONATE NOW" button.

We are continuing to work on improving the Society's website to ensure it is as user-friendly and helpful as possible.

Just some things to check out:

Visit our news section for updates on upcoming CP-related events, seminars and information sessions happening throughout New Zealand

You can now apply for programmes, grants, new membership and membership renewal online

The Research section, for overviews of latest research being conducted in cerebral palsy

We have more exciting content planned, but would love your ideas on how else we can continue to improve our website

Please get in touch on cpsociety@cpsociety.co.nz with any feedback

Join us on Social Media

If you are a social media user or would like to be, make sure you follow our Facebook page. This is a great way to keep up to date with news from the Society, international CP community and other members.



Our page is called Cerebral Palsy Society of New Zealand.



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Upcoming Events

CP Society Christmas events

We're busy getting ready for Christmas events for our members up and down the country. At this stage, we are planning on holding events in the following towns and cities in November - early-December:



- Whangarei
- Auckland
- Hamilton
- Rotorua
- Tauranga
- Gisborne
- Napier
- Wellington
- New Plymouth
- Palmerston North
- Nelson / Blenheim
- Christchurch
- Dunedin
- Invercargill

If you have any other suggestions for where Society Christmas events could be held, please get in touch and we'll do our best to make this happen.

Coffee Clubs

We are hoping to expand our members Coffee Club events to more parts of New Zealand. These are usually held monthly and are a nice way for members to catch up. The Society will cover costs associated with these events (food and drinks), so let us know if you are interested in starting one in your area.



Aside from our existing locations, we are pleased to let you know we have added two new Coffee Club locations:

- Palmerston North
- Blenheim

See our website for further details for times and locations.

The Cerebral Palsy Society NZ 2018 AGM

The CP Society AGM will be held on Sunday 28th October at 2pm. Refreshments will be provided after the meeting.



Requests for Board nominations and remits will be sent by post in August to all members.

This year the AGM will be held in the new CP Society office, 8 Railway St Newmarket; there is plenty of parking.