

The Review

Official Magazine of the Cerebral Palsy Society

August 2019



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Cerebral
Palsy Society
freedom & choice

Cerebral Palsy Society

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New Zealand

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For staff contact details, please go to page 23

Any opinions, findings, conclusions or recommendations expressed in this publication are those of the authors and do not necessarily reflect the views of the editor or the Cerebral Palsy Society of New Zealand.

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News From Our CEO

We have had a busy few months. As you can see the Review is filled with new activities and opportunities for our members.

Communications

Aden Miles, our new Director of Communications and Marketing has been releasing EDMs (group emails); Facebook; LinkedIn and other communications so as to keep you updated on all our events and opportunities. He is also continuing the work with the Youth Alliance on their branding. We have had a strong focus on our infrastructure. The website has been updated you can do most things online; the database behind the website gives us more accurate on time information so we can tailor services better for you.

Events

We have been trying new events, the Mums' nights were a fabulous success and there were strong recommendations to continue them. We are looking for several fathers to start up Fathers' nights anyone interested? Please contact us and we can support you. We have just held as a series of mid-year Christmas dinners instead of at Christmas, as requested by members. We will be seeking your feedback via a survey on your preferred events in your area.

The puberty evening went well we have learned that parents are interested and may not be able to



attend and we have had hundreds view online. We will offer improved videoing of all meetings so people can watch in their own time. We have Iona Novak speaking to the Research Day and doing a parent evening at the office, she will also be videoed and available for your viewing.

Intensive Rehabilitation

The Cerebral Palsy Society has commissioned Price Waterhouse Cooper to research the cost benefit analysis of our current system when compared to more intensive models. This involves scoping what is currently available, (current state assessment); systematic literature review.

The intensive programme model and the comparative cost effectiveness review. Please let us know if you are interested in contributing. We cannot do this without you.

Gilli Sinclair
CEO, Cerebral Palsy Society

2019 ANNUAL GENERAL MEETING

Sunday October 13th

Notice is hereby given that the Annual General Meeting of the Cerebral Palsy Society of NZ Inc.

Will be held on Sunday 13th October 2019 at 2pm at the Cerebral Palsy Society office at 8 Railway St., Newmarket, Auckland

Remits for Consideration and Nominations for the Board must be sent to Gilli Sinclair, Cerebral Palsy Society DX Box CP31005 Newmarket Auckland 1023, or gilli@cpsociety.org.nz to be received no later than September 6th 4pm 2019. (Remit and Nomination form enclosed)

The agenda, financial report and President's report will be available online at www.cerebralpalsy.org.nz ; at the AGM and available by request from October 7th 2019.

Remember, you must be a financial member to vote.

Review Ad Rates

The Cerebral Palsy Society's quarterly Review reaches members and supporters across New Zealand and it's a great vehicle for advertising your small business, organisation or event.

RATES are as follows for print-ready ads:

- Half page ad, inside page - \$250
- Full page ad, inside front or back cover - \$400
- Full page ad, outside back cover - \$500

NB - Reduced rates for inclusion in all 3 Reviews/year are available on request.

To place an ad, or for more information, please contact Aden@cpsociety.org.nz

September Is Open For Registrations

We're proud to announce that registrations for September, which runs from September 3rd to 30th this year, are now open at www.september.co.nz

As many of you know, September is the CP Society's biggest annual fundraising campaign, in which people dance, roll, walk, surf, cycle, or swim the equivalent of 10,000 "steps" each day for 28 consecutive days. Approximately 40 activities can help you achieve this daily goal and, if you use a manual wheelchair or walking frame, an odometer can track your rotations.

Registration for the event is \$25pp/\$100 for a team of 4. As a participant, you will receive a pedometer to track your progress, as well as fundraising tips which will be easy to put in place.

We have made the difficult decision this year to discontinue both early bird and member discounts because we cannot afford to subsidise participants as we have done in past years. It is imperative that we raise as much money as we possibly can, in order to provide enhanced services to you, our members, as well as funds for research. We appreciate that some of you will be disappointed by this news. We do not want you to be prevented from participating and raising funds, so will reconsider this new policy on a case-by-case basis, if you get in touch with us. Please email sue@cpsociety.org.nz.



This year, September is going to be bigger and better than ever – it is now running in 7 countries: New Zealand, Australia, the United States, the Netherlands, Singapore, Turkey and France. Here in NZ, you'll hear about September through The Review, our regular emails (EDMs), and the CP website, plus Instagram and Facebook (CP and September pages) AND if you tune in to Coast Radio, the HITS, or the Mix, or read The NZ Herald, you'll hear even more. With both regional and national coverage, September is providing a great opportunity to raise awareness of, and funds for, CP.

Why not put together a team of four from amongst your family, friends or work colleagues? The CP Youth Alliance is already fielding two teams for September and engaging in some friendly competition and all of our staff will be participating and raising funds. We hope that you will too, if you can; or please consider inviting others to participate on your behalf. The more money we raise, the more we can do for you, our members.

Dr Iona Novak To Hold Research Events At Cerebral Palsy Society

With much anticipation, the Cerebral Palsy Society of New Zealand is hosting Dr Iona Novak for our research event seminars.

Dr Iona Novak from the Cerebral Palsy Alliance Australia will be presenting an evening with parents and a researcher seminar on August 2nd.

Dr Novak is one of the most pre-eminent Cerebral Palsy researchers in the world. She is part of a team investigating key cerebral palsy interventions such as the role of stem cells, neurological regeneration and the role of magnesium sulphate in protecting the infant brain.

Furthermore, Dr Novak is known for her engaging teaching style and her absolute commitment to share information with CP families.

Dr Novak also has a background in occupational therapy with research expertise in conducting clinical trials and research registries. She is an Associate Professor and Head of Research at the Cerebral Palsy Alliance, School of Medicine, at the University of Notre Dame in Australia. Lona oversees the research activities of the Institute and provides leadership to the Australian Cerebral Palsy Register.



Her research interests are in evidence based practice; intervention efficacy; knowledge translation; home programmes; botulinum toxin and population studies leading to the prevention of cerebral palsy.

We are incredibly excited about facilitating these events for the community.

Key Information

Date: 2nd August 2019

Venue: CP Society Office
8 Railway Street
Newmarket
Auckland 1023

Time:

Researchers Seminar 10am to 2pm

Parenting Evening 7pm to 9pm

Haunted Hogwarts Charity Fundraiser In Wellington To Benefit The CP Society

October 30th & 31st, Wellington SPCA, Newtown

Those in Wellington during the Halloween period are cordially invited to a magical family-friendly haunted house. Held in the spooky old Fever Hospital (now the SPCA, in Newtown), you can expect frights and fun in this Harry Potter-themed event.

We're honoured to be the chosen charity for this fundraiser organised by Mindy Dalzell of Twig & Arrow and her team of amazing helpers. All proceeds from the event will be donated to the CP Society. Twig & Arrow are organising a fantastic event, but they need our help. We're looking for volunteers to assist as follows:

Tuesday October 29th, after midday for about 3 to 4 hours: 2 to 3 strong people to help with pack in.

Wednesday 30th and Thursday 31st: 2 people each day and night, to help run check in from 2:30pm till 9pm or (two groups of 2 in split shifts like 2:30 to 5:30 and the next set does the 5:30 to 9:30); you will not be counting money, just looking up the name and ticket number from the list and handing out a lariat to each guest.

Finally, after 9:30pm on the 31st, we'll need as many volunteers as we can muster, to help with take down.

Also, there is some talk of running a sausage sizzle and also handling donation buckets, to raise more funds for CPS, so that would involve more volunteers as well.

If you are available for any/all of the above times, please get in touch with Will as soon as possible: will@cpsociety.org.nz

And, Twig & Arrow have generously donated 20 tickets to CPS to be given to Wellington CP families to view the first show (6-6.30 PM, October 30). Email us with "Haunted Hogwarts" in the subject line if you are interested in free tickets to this event. Please be aware that these tickets are limited and will be distributed in a way to allow the maximum number of CP families to attend, with priority given to CP member families.

We'd love to see you there, as a volunteer or as attendees. Full details can be found online. You can also visit the Haunted Hogwarts Charity Fundraiser Facebook Page for updates.



Clinical Network for Cerebral Palsy

Exciting news! Cerebral Palsy has been approved as a clinical network. The Ministry of Health has contracted with the New Zealand Paediatric Society to provide a range of Clinical Networks.

Paediatric Society of New Zealand (PSNZ) is a membership organisation of health professionals working to progress the health and wellbeing of children and young people throughout New Zealand.

A clinical network is a linked group of professionals and organisations working together in a coordinated manner with clear governance and accountability arrangements.

Structured Clinical Networks offer a way of linking services, or programmes, so as to achieve a continuum of care along which patients and their families travel. Through shared understanding, they enable better co-ordination of services along the continuum of care involving primary, secondary and tertiary services. A clinical network is designed to support best clinical practice at all levels of service provision.

This is one of the first New Zealand networks co-lead by a clinical group and a membership organisation. The purpose of this group (this needs sign off from the Governance group) is to:

- Develop and promote best practice recommendations and resources for health professionals that support early diagnosis, early intervention, and effective management of Cerebral Palsy
- Provide children's voice and young people's voice to our planning.
- Design and develop improved transition from paediatrics into adult services
- Support the development of a sustainable pathway for the NZ Cerebral Palsy Register so that data from the Register can feed into other work streams
- Create comprehensive understanding of key aspects of SDR and intensive therapies amongst DHBS and Ministries
- Promote active participation in all aspects of life for people with cerebral palsy
- Establish a workforce education and development programme
- Develop a system for the monitoring and auditing of services to inform continuous quality improvement
- Identify and liaise with national and international bodies with relevance to childhood Cerebral Palsy

We are in the process of establishing this with an expression of interest going out to all clinicians and therapists throughout the country. CPS is also seeking expressions of interest from members with CP and parents to ensure every piece of work we do reflects the needs of children and adults with CP and their families.

Please let us know if you are interested in participating by emailing gilli@cpsociety.org.nz.

Family Corner



The Cerebral Palsy Society's Family Support Manager Gemma Overton gives an update on CPS activities!

I have been out and about meeting our families across NZ including the Christchurch and Auckland Mums' evenings, the Wellington Coffee Group and the Napier Mid year Dinner, along with planned family visits.

I am really enjoying meeting our families face-to-face and being able to support them in any way I can. It is great to be able to network and, through meeting families, assist other families by passing on new information and creating connections.

We have had a great response from members who have taken

advantage of the Compression garment, weighted blanket and Vibration plate offers through the getThis&That Scheme.

It is wonderful to see that we are giving more freedom and choice in the programme.



Manuele's Fitness Solution

In 2017 I was introduced to COGY, a pedal-wheelchair. As seen in my picture, I can sit on it and pedal with my legs to move it. I use the handle (which I'm holding) to steer the COGY. When I first tried a COGY, I fell in LOVE with it. It was fun. It was a great workout for my legs and it was easy to get in and out of. I also felt safe riding on the COGY independently with minimal assistance.



my walking frame, but I don't always feel secure to do so independently.

Fitness dilemma



I usually use an electric wheelchair to get around on a daily basis. I feel comfortable and secure to independently go

to and fro in my electric wheelchair.

It requires no effort, apart from one hand to control a joystick to command the motor which direction to go. Sometimes I use a walking frame when someone is available to supervise and be near me. I lean against the frame and walk to push the frame in the directions I wish to go. Depending on whether the surface is uneven or flat, I need more or less assistance. I am exercising my legs using

A wonderful solution

COGY was a great solution to the dilemma I had. I feel almost as comfortable and secure as I do in my electric wheelchair. My feet are strapped in and I have a waist belt so it's pretty secure. But unlike my TDX SP, the COGY is powered by my legs. The COGY is heavier than my walking frame and with more wheels providing more stability. So, I don't have a fear of tipping over on various surfaces.



I wanted my own! Like all great gadgets, they don't come cheap. So, I had to find a total of \$6000 somehow. I got the idea from friends and others to start a Give A Little Page. Many people I know, and don't know, were supportive and so I raised the money within three months!

Round the Bays in a COGY?

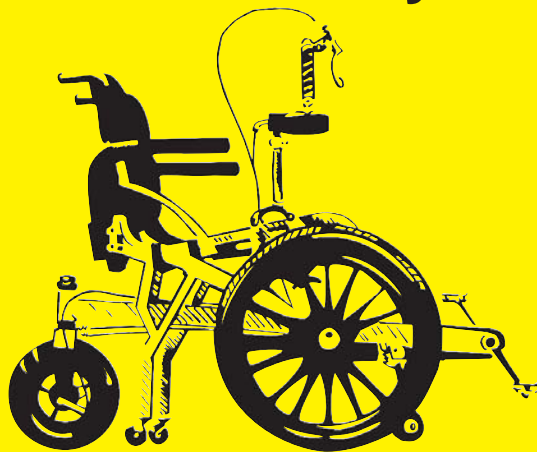
Koko, the COGY distributor in Aotearoa, brought a COGY to my place to trial a few times. On one of my trials, I asked Koko if anyone done Round the Bays on a COGY before? A bit to my surprise she said yes. This instantly made me want to make this my goal, as I was going to ask if doing the 8.4km course on a COGY was a good idea. I've always known about Round the Bays but never participated in it, mostly because I'm unable to walk or run. It would be too hard and painful for my body if I walked 8.4km in my walking frame. My upper body gets

tired from leaning on the top after short distance. Walking a couple of kilometres wouldn't be a wise thing to do, even with someone beside me. Also, I wouldn't feel that I've achieved anything if participated in Round the Bays driving my electric wheelchair. I would just be draining the batteries.

I knew from my first few COGY trials that I could potentially pedal long distances. I'm not using all my muscles, but only the ones in my legs and left arm. So, I won't get too tired or sore which makes training for and participating in Round the Bays feasible. I began training straight away.

Note: This article was written by CP Society and Youth Alliance member Manuele Teofilo.

Your disability disappears?!!



Fun + safe

Light + transportable

Easily manoeuvrable

**Proven
rehabilitation tool**

**Suitable for
tight indoor spaces**

**Stable for outdoor
curbs+bumps**

COGY

COGY New Zealand
gocogy@gmail.com
kokocogy Q

Pedal Wheelchair trial/rental/purchase
PO Box 12526, Auckland 1642
kokocogy.wix.com/gocogy

Cerebral Palsy Youth Alliance Progresses



The Cerebral Palsy Youth Alliance is making progress and adding to its collective identity in the process.

This dynamic group of individuals is striving to give a collective voice on youth issues from the perspective of young people with disabilities, and has designed and implemented a new logo. The logo encompasses the values of inclusiveness, people, progression and unity.

The group is also scheduled to begin filming the Code of Freedoms which is a series of statements which speak to the choices, decisions and outcomes that they believe all youth, but especially those with disabilities, are entitled to.

The engaging videos

will be used as an internal and external resource for the Cerebral Palsy Youth Alliance and Cerebral Palsy Society to educate, inform and engage the community. Members will also be involved in media training next month.

Over the last few months, the group has continued to meet monthly, and has welcomed new members with specified roles. We have an equal gender balanced leadership board, and have held mentoring, leadership and governance workshops and developed a professional pathways for youth with CP.

Dr Huhana Hickey is one of the guest speakers who has spoken to the group.



Emma Taking Flight To Encourage Diverse Representation

Emma Cooper - Williams is a member of the Cerebral Palsy Society Youth Alliance and has political aspirations to make a difference. CPS recently spoke to Emma on her thoughts around diversity, inclusion and equitable accessibility.

"I hope to soon be a young person with a disability in Parliament. I've previously been the chair of the Princes Street Labour Party branch, women's organiser and one of the Region 1 Young Labour representatives. I'm very interested in developing social policy that is innovative and stretches to provide positive impacts to as much of our society as possible," Emma's statement of intent.

The driving forces behind her political awareness result in listening to and representing the needs of the community to create a more equal society.

"As a country New Zealand has made progress in recent years towards understanding the needs of diverse communities, but we need to do more. I want to also make sure that the voices of people with disabilities are heard and that lived experience is represented in New Zealand Parliament," Emma added.

Having cerebral palsy has offered Emma insight into a multitude of areas of policy where improvements can be made.

"These aren't limited to the health system, as I believe it is an interdisciplinary approach that

will serve our diverse society the best. Although my disabilities have motivated me towards this philosophy, I don't feel my disability has been the ultimate token driving me towards my goals in politics.

"I would love to see Parliament and systems of governance around the world become more accessible for people with disabilities, young people, and be truly representative of our culture. Moving away from elitist political institutions will serve us well as a progressive society in the near future," she explained.

Emma is also a current member of the Cerebral Palsy Youth Alliance, a progressive extension of CPS which has a specific focus on youth living with cerebral palsy.

"I think there has been great progress made by the Youth Alliance. We have come together with diverse views and opinions showing that no two people with CP are the same. We have carried out responsibilities and really developed a passion for making a difference for a wider sphere of influence, rather than just being self contained."

As a member of the Youth Alliance, Emma intends to offer more leadership and to share her experiences, not just of disability, with the wider community and encourage young people towards a sense of enhancement and self-determination, to open their eyes to the difference they can make in Aotearoa New Zealand and the world.

CPS Grateful For Continued Support

The Cerebral Palsy Society of New Zealand acknowledges the continued support from the community and stakeholders which enables further opportunities for its members.

The Ministry of Youth Development has provided two rounds of funding, totalling \$50,000, for the Youth Alliance which is significantly impacting the experienced CPS has to offer its members.

CPS Youth and Pacific Advocate Jordon Milroy said the partnership with MYD has been valuable for the Youth Alliance and the work it delivers.

The funding is allowing the Youth Alliance to develop their own leadership style, the Freedoms which is a code of rights for young people, training and mentoring, leading into a mentoring programme for young people with cerebral palsy, and developing and practicing skills in governance to best prepare them to occupy board positions in the future.

“The MYD partnership provided an opportunity to improve the youth voice within the Cerebral Palsy Society and the wider New Zealand context. Mentoring, leadership and employment training are the positive pathways to success. The partnership will transform this blueprint of the Cerebral Palsy Youth Alliance across the country,” Mr Milroy said.

The organisation also recently received funding from New



Zealand Community Trust (NZCT) to purchase three COGY bikes for members to experience and trial.. NZCT awarded funds to the Cerebral Palsy Society of NZ Inc to allow the purchase of three specifically designed bikes.

CPS Chief Executive Office Gilli Sinclair said: “The funding of these three bikes is significant. They will be housed within the organisation so people can come in and try them. Our members can also take them home for a short period to trial them.

“What this funding allows is for CPS to continue to offer our members difference experiences.”

The COGY is a transformative development in transportation for individuals living with cerebral palsy, that is powered by the user’s legs. It securely straps the feet and has a safety belt which sits around the waist. It is also heavier than other walking frames and has more wheels which provides more stability.

Note: Featured in this edition is also a story on one of our Youth Alliance members, Manuele Teofilo who is training for Round The Bays using a COGY.

Creating Unique Mobility Dog Partnerships

Mobility Dogs has been raising, training and placing service dogs for over 10 years. Our primary goal is to assist people living with a disability by partnering them with a Mobility Dog. They recognise that no disability or dog is the same, therefore each Mobility Dog partnership is unique.

Over the years many of their clients with cerebral palsy have been partnered with a Mobility Dog. Their dogs have full access rights under the Dog Control Act which means they can go into public places, for example: on public transport, educational institutions, employment environments, restaurants, movies and so on.



Each dog is trained to:

- Retrieve and carry items – such as help load and unload the washing.
- Deliver items to a person
- Open and close doors and drawers
- Press buttons for elevators and pedestrian crossings
- Help with payments in shops
- Assist with daily activities such as dressing and undressing
- Turn lights on and off
- And plenty more tasks which are specific for the individual's needs

Interested in how a dog might work for you:

- Are you over 18 years of age?
- Are you able to care for a dog? Dogs need love, companionship, food and exercise. They are social animals and just want to be with you. It's a big commitment!
- They accept enquiries from all over New Zealand, however their focus at the moment is in the greater Auckland area.

Apart from all the specialist tasks they dogs are trained to do, they also provide emotional support, a sense of security and a connection to the community. Working with a Mobility Dog can be a life changing experience.

Mobility Dogs would love to hear from you if you feel a Mobility Dog may be right for you.

If you would like more information, please get in touch by email applicants@mobilitydogs.co.nz

Adaptive Movement Encourages Overall Health



FAM™ (Functional Adaptive Movement™) is a strength and conditioning social enterprise with specifically designed programmes for all ages to increase the overall health and wellness of those dealing with any disability.

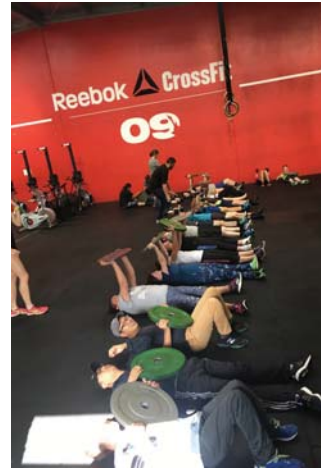
These programmes have proven to elevate the balance, coordination, confidence, strength, endurance, concentration, communication, capability, and life skills of participating "differently-abled" athletes.

Currently, about 200 adaptive athletes are attending classes each week, yet the swell of interest in the unique programmes of FAM™ have encouraged plans to expand the programme further within New Zealand and internationally.

Working out of two respected CrossFit facilities in Auckland, FAM™ utilises active volunteering from the Community and Corporates' social programmes, local Universities and Allied Health bodies to deliver fun-filled and energetic classes, while ensuring the safety and personal achievement of all participants.

The FAM™ programmes and community focus intentionally on a united culture and the belief that there are endless possibilities for all of our athletes and their affiliates.

For more information on FAM™ go to www.functionaladaptivemovement.com. You can contact them by phonig 021 82 6453 or email info@functionaladaptivemovement.com



FAM™ Program (Functional Adaptive Movement™)



STRENGTH and CONDITIONING Program:

specifically designed to increase the overall health and wellness of those dealing with any disability. These programs have proven to elevate the balance, coordination, confidence, strength, endurance, concentration, communication, capability, and life skills of participating "differently-abled" athletes. Offering the opportunity for all athletes to live more independent lives.

www.functionaladaptivemovement.com

Contact Michael at info@functionaladaptivemovement.com to get the full roster!

Pathway To The Halberg Games

The Halberg Games is an annual, action-packed three-day sports event held in October.

Each year ParaFed Auckland takes a team of athletes from the Auckland region to the Halberg Games to enjoy the fantastic experience of representing our region together.

Being a part of the ParaFed Auckland team also means you get to access exciting pre-games training sessions with special guests, team social activities and events to get to know one another, a full team kit, as well as the opportunity to stay on site for an authentic Games village experience!

The team is working hard to finalise the details for this year's training programme which will be kicking off in August, however in the meantime, they are now taking expressions

of interests to join our Auckland Halberg Games Team.

ParaFed Auckland believes every child with a physical disability should have the opportunity to take part in regular physical activity and sport, and they believe the Halberg Games provides a fantastic opportunity to get involved!

ParaFed Auckland's 2019 goal: to have the biggest ParaFed Auckland Team to ever attend the Halberg Games.

They will be running and promoting a wide range of sports and activities prior to the Games to build some of the skills needed during the event, as well as to encourage regular physical activity.

They also want to get everyone moving and excited for the Games and we believe it is a





great way to build on the Parafed Auckland Team Spirit.

Make sure you keep an eye out on the Parafed Auckland website for exciting updates on the Team Parafed Auckland training programme.

Junior Programme

They strongly believe that every youth with a disability should have the opportunity to try new things and to take part in regular sporting and recreational opportunities. They want to provide a gateway for young people to try new sporting and recreational opportunities that they may have otherwise not had the opportunity to do so, with the hope that they go on to participate regularly in activities of their choice. With a partnership with Auckland Wheelstarz, Touch Compass Dance and Extreme Edge Rock Climbing,

they are extremely satisfied by their activities for the quarter two programme: Wheelchair Basketball, Hip Hop, Youth Theatre, and Rock Climbing. The programme is open to anyone aged 5 - 21 with a disability looking to have an introduction to new activities alongside other young people and their families.

Becoming a member of Parafed Auckland

Parafed Auckland is unique from the other regional Parafeds in that clubs and organisations can become members of Parafed. You have now the opportunity to join as a member, there are six options to become a member of Parafed Auckland. They currently offer a wide range of benefits depending on your membership, from discounted rates on equipment hire to tickets to an Awards dinner.

Innovation Continues To Provide Benefits For Members

The Cerebral Palsy Society of New Zealand is pleased to be able to offer the opportunity for members to use their getThis&That vouchers for this financial year, and the next (a total of \$400 value) to purchase a LifeBack II vibration machine to use at home. This has been made possible with the support of Lloyd Shaw of Vibra-Train CardioTech.

You may have read about members gaining mobility through Vibration Machines.

The LifeBack II is easy to use, even for some people who use wheelchairs. Lloyd's suggested programme ensures authentic whole body vibration at a speed that the brain and body can tolerate. Using it at the lowest speed is vital; and this is far more comfortable and tolerable than some other units available.



These low-profile total surface vibration units were designed to get around previous limitations of far more expensive machines marketed to disabled people, (where only the centre piece vibrated). LifeBack II machines can be used in a Pivotal or Lineal fashion which can get around certain wheelchair designs.

Regular use (at least ten minutes a day can be beneficial in many ways):

- Weight Loss
- Circulation
- Relaxation

It may also help with relieving tension and pain, and improving balance and mobility, depending on the type and severity of cerebral palsy effects.

Conditions of offer:

- You need to be a current financial member and a financial member for 2019-2020.
- CPS will combine the two years of getThis&That to pay for this if you have not used your vouchers or applied for gT&T. Please check with Jacqui at jacqui@cpsociety.org.nz
- If you have used your gT&T, we can sort out the difference with you.

The unit MUST be used as directed for best results, please contact Lloyd Shaw of Vibra-Train lloyd@vibra-train.com when you receive your order confirmation, to get specialist advice.

Joseph Gets A Move On Thanks To Funding Grant

With the assistance of a funding grant through Cerebral Palsy Society of New Zealand, Joseph Leet is now competing at his potential with a new bike.

Joseph's mother, Debbie Leet, said Joseph is loving his new bike and that it has opened a new world to him.

"All our lives we have had to fight tooth and nail to be able to help Joseph reach his milestones in life. Life for him has not been easy, often sitting on the side lines watching other people achieve their goals and learning to accept that, because of the limitations handed to him, he probably would never do a lot of things that others take for granted on a daily basis," Debbie said.

In September 2018, Joseph completed his first 10km bike ride, participating in the Hamilton Half Marathon. While being cheered on by friends and family, Joseph placed third in his category.

"In October 2018, Joseph also joined in a fun bike event, the Rotorua Bike Festival. He had so much fun cycling up and down the Rotorua Airport runway. It was cool that both his mum and dad could bike beside him," Mrs Leet said.

Joseph currently attends Avantidrome in Cambridge every Tuesday and Wednesday as part of the Trikes group, which is the highlight of his week.



"It is because of people and organisations like yourselves, that Joseph has been able to gain some independence, self-worth and feel some normality in his life. We haven't, and never will, forget your kindness and generosity shown towards him. It is because of you people that Joseph is the happy young man that he is today.

"I know we have thanked you before, but we will never be able to thank you enough for helping Joseph get his dream bike and accessories," she said.

Mrs Leet added: "It is so nice to know that there are still some lovely caring people out there in the world."

Content from this article was extracted from a wonderful letter that CP Society received from Stephen and Debbie Leet.

Advocacy Connects Organisation With The Community

As a means of ensuring connectivity with our members, we have a dedicated advocacy model in place.

Cerebral Palsy Society's Michael Northcott is the organisation's new advocate and part of his role is to meet with members each week to hear their stories, concerns and issues.



"There are similar trends that I am hearing from members when I meet with them, and they are around transport and staffing.

"I have worked for a number of businesses, including organisations in the disability field, prior to joining the team at the CP Society. I want to help enable our members to live better lives, and I think that the programmes the Society offers make a real difference to our members." Michael fulfils many roles including answering many of the incoming calls and queries. In conjunction with Auckland Transport, he carries out Total Mobility assessments. "I coordinate a number of projects including the getOnYour Trike programme, purchasing equipment and IT assistance for the office, and at times, for members."

Cerebral Palsy Society pushes

for big outcomes that reflect the voice of those in the community. We are actively engaging and communicating with regions across New Zealand which is enabled by our connections events.

With your help and support CPS will continue to be ardent advocates for people in the community, ensuring their voices are heard.

We will also continue to actively develop links, and talk to the community and our members about what they need. We will engage with partners and government in order to positively move things forward.

If you need more information or would like advocacy, please contact Michael by emailing him at michael@cpsociety.org.nz or call the office on 0800 503 603



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