REVIEW

The Official Magazine of the Cerebral Palsy Society of NZ Inc August 2017

The RaceRunners ™ are here, so if you are wanting to challenge yourself this summer then turn to page 10

Cerebral Palsy Society

Cerebral Palsy Society of NZ

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CP Society Mid-Winter Dinner at the Cardboard Cathedral

Christchurch

Gilli Sinclair, Michael Northcott and some of our Board Members joined Christchurch CPS members on a cold and wet winter evening for the Cerebral Palsy Society Mid-Winter Dinner at the Cardboard Cathedral.

Everyone soon warmed up once inside the cathedrals majestic setting and enjoyed the fabulous food, a bit of dancing and some sparkling companionship.

We acknowledge and are very grateful to the following grant provider, Pub Charity, that made publication of this issue of the REVIEW possible

News from Headquarters

I hope you are keeping warm and healthy over winter and enjoying the beginnings of the days getting longer.

Since April, we have been working hard to continuously improve our programmes to better serve your needs and also improving the support we offer to ensure it is relevant.

Our work under **People** will include improving services and programmes to you, extending coffee clubs and events across the country; working with members to ensure the programmes meet your needs. This year, we are focusing more on improvements, based on your feedback, for getStructured, the Trikes and getUpAgain.

Advocacy and Voice will increase support for people interested in advocating for the CP cause; we will work co-operatively with the Ministries and other disability sectors. We have set up meetings with parents, young people and other like minded physical disability sectors.

Innovation & Development allows us to work with members to provide innovation and newly designed support to future proof our organisation. Areas included here are Respite; Research; Youth Alliance; more support for families with newly diagnosed children. We have also had opportunities to look at the walking bikes and offered places on the Jubilee Trust's accessible boat- the Tenacious.

We have been working really hard on the website- looking at extensive improvements to make life easier for you and us all.

Finally we need to ensure we have funding to support our current programmes and provide you with the services support and programmes that are relevant and useful. We need to do this without using our capital base to pay for all our programmes so we have a comprehensive fundraising team who are developing sustainable and viable funding streams. **Steptember** is starting soon and we are excited to be starting our stepping/ swimming or exercising.

Finally, please find enclosed details of our AGM- planned for October 29th in Auckland. We welcome you all there and we welcome any nominations or remits you are interested in proposing.

I hope you all have a great winter - *All the best Gilli Sinclair*

Medical Cannabis

Recently I went to a meeting hosted by the Green Party Health Spokesperson, Julie Anne Genter. Her Members' Bill has been drawn from the ballot to possibly progress to the next stage of select committee hearings. She was looking to elicit interest and support from organisations with members who may benefit from the bill being considered and it eventually being passed.

This bill would make it legal for individuals to cultivate or nominate a designated provider to cultivate small amounts of cannabis plants for medicinal purposes. Registered medical professionals would be responsible for offering the authorisation and assessing the merits of individual patients. Currently, the only access to medical cannabis is through health ministers authorisation and even then, the drugs are expensive at $1,200 per month. The consequence of this current system is that many individuals self-medicate with types of cannabis that can have unintended consequences. Unless they are guaranteed connections to a reliable and ethical grower, people have no ability to assess dosage, chemical compounds or particular strains.

There is robust scientific evidence that medical cannabis can be an effective tool in combating a multitude of conditions. In particular, some of the intractable side effects of chronic illness such as pain, loss of appetite, seizure disorders, and spasms. While it is by no means a magic bullet, many patients have reported that it is more effective with less side effects than traditional opiate medication. Specifically, it does not seem to disturb the bodies other systems and processes as much as the medications that are currently available.

Crucially, this bill is not advocating a free for all, nor will it leave select committee without considerable regulation.
This bill follows the Canadian and Hawaiian models quite closely. In this framework, access to this option would be determined on medical merits. It would also allow robust scientific studies on things like long-term effects, ideal dosage, and contraindications. Currently, it is difficult to conduct scientific inquiries because almost all forms of cannabis are prohibited under the Misuse of Drug Act. The Greens are looking to lobby Members of Parliament to consider letting the bill at least reach Select Committee so that the case for medical cannabis can be put before appropriate experts and debated properly.

Please let me know if you would like further information on these efforts or if you would like to offer your stories on accessing pain management treatments. This can be done confidentially if you would prefer.

-Amy Hogan and Mary attending the meeting on Medicinal Cannabis in NZ.

Whole Body Vibration Workshop

Recently, I attended a full day Whole Body Vibration Workshop hosted by Chad Timmermans of TheraSuit Australia. The methods have shown some promise in treating Cerebral Palsy symptoms, both mild and severe. Therefore, it was interesting to get a look at both the scientific basis and practical application. I was also given contacts for organisations who are using vibration plates if anybody would like to arrange a demonstration.

The basic principles of vibration therapy are that it works on the reflex function of the nervous system in order to provide an increased level of control in the musculoskeletal system. This technique is used across multiple domains such as sports medicine but has shown some promise with the postural and movement difficulties inherent with Cerebral Palsy (CP). The majority of the research is centered around mild to moderate CP and the improvements to standing, walking and activities of daily living. However, several clinics have begun working with level 4 and 5 CP as a way to promote better postural control, reduction in bone deformities, and a reduced level of chronic pain and spasm.

The three main approaches to vibration therapy demonstrated in this workshop included promoting the right forms of muscle activation, core strength and proprioception (neural feedback), and stability and balance. For example, even though I was supervised, I found it particularly challenging to be asked to balance standing up without holding onto anything, as I had never done that before. However, I was eventually able to achieve a standing position with progression and persistence.

It was interesting in the workshop to witness their non-traditional approach to CP in general. From this framework, individuals with CP need to be subjected to high-intensity training that is ideally around 16 hours per week. These training schedules are broken into intensive blocks and maintenance programmes. The work is viewed as high-performance training rather than the more conventional language of symptom management and deterioration control. It is quite a refreshing change to see such an idealistic approach to a condition that has often been seen as static. However, much more scientific investigation needs to be undertaken in order to assess the long-term benefits, potential risks and optimal amounts of time in clinic. - *Amy Hogan*

For more info or to contact Chad Timmermans go to timmermansmethod.com.au

Walking Bikes for sport, play, exercise and a more active life

Whether you call it a "Walking Bike "or a "RaceRunner™" it is great fun and can offer some users a freedom they have never previously experienced.

A RaceRunner™ is a custom-built tricycle "learner bike" without pedals.
They can give anyone, who normally only gets around in an electric wheelchair, manual wheelchair or walker the opportunity to move under their own power at relatively high speed.

The development of RaceRunner™ bikes was initiated by Connie Hansen, an occupational therapist and Paralympic multiple gold medalist. Today RaceRunning, a Danish invention, has become an innovative sport for disabled people with impaired balance.

Amy and Travis have rigorously trialled the bikes so if you have any questions from a CP point of view they can probably answer it.

Otherwise, if you are feeling bold and want to try a bike, contact Michael in the office and have a chat.

CPS has imported into New Zealand three bikes in small, medium and large. The bikes are weight rated, so you will need to know your current weight and height, so we choose the correct bike for you.

"I love to feel motion and freedom. Seeing friends and family out RaceRunning or on walking bikes – experiencing the same feeling, makes me truly happy." – Connie Hansen, founder of By CONNIEHANSEN ApS - www. by-conniehansen.com

Photo-by-Kristian-Kristensen-lille

Disability Support Services Consumer Consortium Report

March 29 – 31 2017

The first meeting of the year was opened by the Minister of Disability Issues, with the rest of the three-day meeting being quite intensive, covering many subjects, some of which are listed below.

NICKY WAGNER - MINISTER OF DISABILITY ISSUES

She spoke of her role as being one of co-ordination in the effort to give disabled people more choice, more control, and more opportunity. She covered such areas as the Enabling Good Lives project and the roll out commencing nationwide (starting in Mid-Central, i.e. Palmerston North) and hoping to be completed in 2018, and the System Transformation and the NZ Disability Strategy and how it is attached to the Disability Action Plan with a framework of targets and measures. One more interesting thing mentioned was that they were exploring the options for a photo ID card that was not driver's license or passport.

Disability Support Services update

This covered a number of strategy updates, such as Provider Forums, recruiting new staff and the System Transformation. In the transformation, they looked at the way Provider Forums addressed the following: What is their role? How will services be funded through clients? In addition, what will it mean for the customer changing from Ministries to disabled people? Other subjects were: increasing demand for goods and services, the shift from general services to Individualised Supports, client self-determination and self-direction.

Respite Survey Findings

The findings were presented with the results from the Respite Survey, with very positive responses. The survey had 1268 responses with overall very positive responses. There was discussion about change of word for respite, yet no final decision was made. In addition, there was discussion around shortage, and dealing with complex and high needs people.

The Code of Health and Disability Services Consumers' Rights

This presentation was about making changes to Right 9 in the code, – Right 9 extends to research and teaching. As some researchers want to conduct research involving participants who are unable to give informed consent , this covers those patients who are unconscious in ED, patients in ICU, severely intellectually disabled people, and people with advanced dementia.

Discussions were around best interests – are participants better off being involved in research that they will benefit from. In addition, is it ethical? And the fact that a Welfare Guardian or EPOA (Enduring Power of Attorney) can only consent to a medical experiment if the experiment is to be conducted for saving the life or preventing serious damage to their health. If no one can consent for the patients, then the researchers have to rely on Right 7(4) of the code. A copy of the HDC case studies is in the consultation document. http://www.hdc.org.nz/the-act--code/right-7(4)-consultation

Independent Living Strategy

This strategy was also undergoing a review as part of the system transformation. The presentation covered the guiding principles for the strategy which includes: self-determination, beginning early, person centered, ordinary life outcomes, mainstream first, mana enhancing, easy to use and relationship building.

The presentation looked at services right now in terms of how well (or not) they are meeting the needs of the people accessing the services. Also looking at mechanisms that seem to take people from home straight to residential care, rather than more supports in other options such as Supported Independent Living or Choices in Community Living. They where keen to hear and understand what drives those choices, and for disabled people to have real choice within the level of their funding.

It was explained to the group that when the Ministry started to develop the Supported Living Strategy, it was apparent that several other services could be included within its scope. They included: home and community support services, supported living, choices in community living and flexible disability supports. The Ministry has received feedback that the strategy needs to:

- be person centered
- maximise flexibility
- focus on whānau & community
- support provider capability, capacity and preparedness

The presenters were also well aware of significant challenges that lie ahead e.g. for providers in having to offer their services to discerning consumers, and for some families who may have to contribute natural supports in helping consumers find providers, and having providers be prepared and ready to transition to a new form of residential care as well.

New Zealand Disability Strategy

This presentation was about how things have evolved since NZDS 2001 and the fact that it did not have enough teeth.
It outlines what New Zealand aims to achieve to meet our obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
It is a guide to the work of government agencies on disability issues and it sets out the priorities that are important to disabled New Zealanders. The main priorities and eight key outcomes for change are education, employment and economic security, health and wellbeing, rights protection and justice, accessibility, attitudes, choice and control, and leadership. The discussion was around that we are in a different space and things have changed. The vision is around the use of the word non-disabling rather than enabling as it fits with context at this time re: Social Model of Disability. Things that came up were around making mainstream supports and services inclusive of and accessible to all, and services and supports specific to disabled people available.

UN Convention on the Rights of Persons with Disabilities

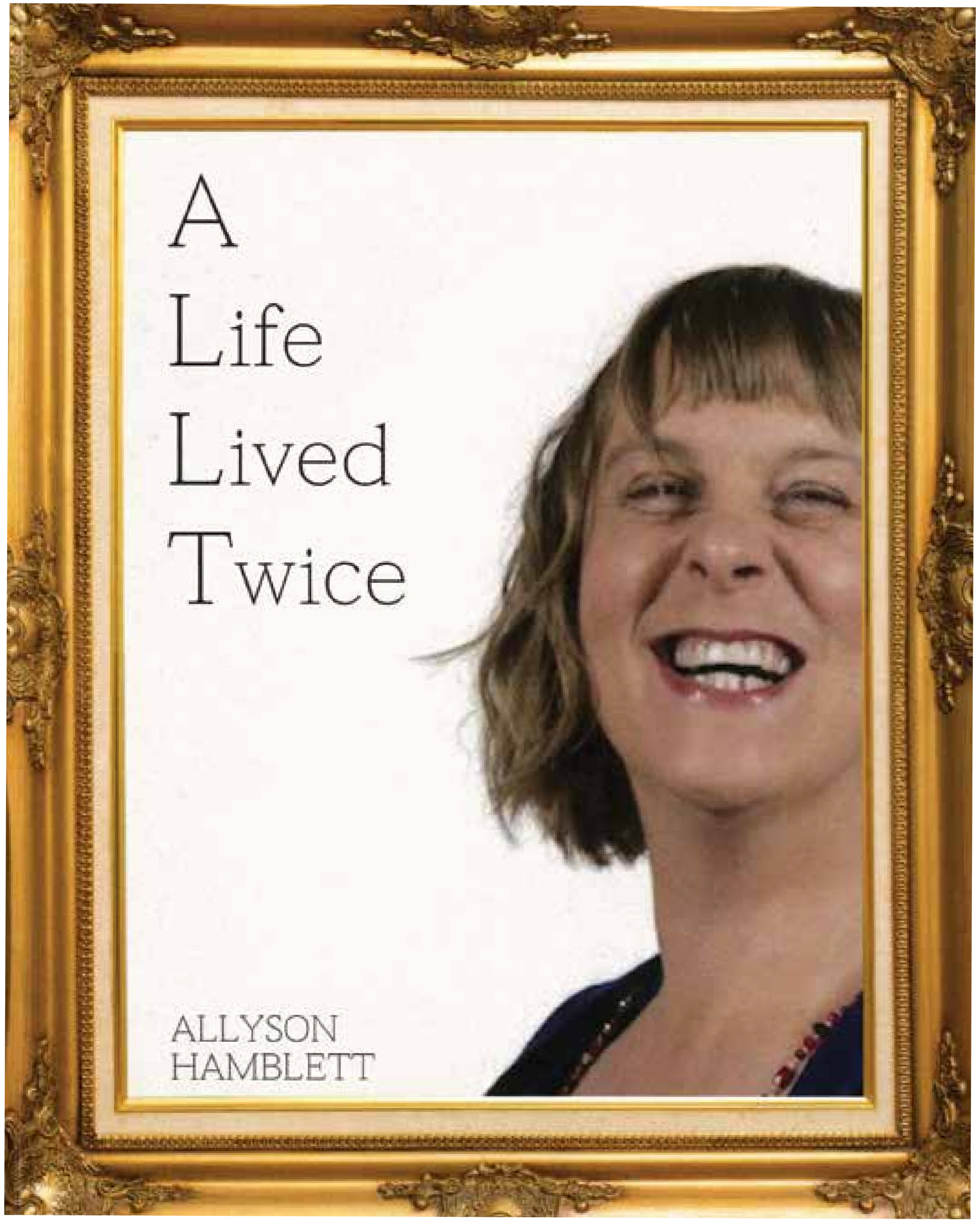
This presentation was a review of how well New Zealand is implementing the UN Convention on the Rights of Persons with Disabilities. It explain how it all fits together, how the UN Convention and Committee on the Rights of Persons with Disabilities works, that New Zealand gets reviewed by the UN Committee every 4 years, and that the purpose and workings of the review is to make sure that New Zealand is implementing the UN Convention.

International Initiative for Disability Leadership (IIDL) 2017 Leadership Exchange

This presentation was a background on the IIDL - an international network that provides a forum to bring together members, to learn new ideas and innovations, and is focused on leadership skills. The last theme was around information sharing, personalisation and lived experience. The network includes policy makers, funders, disabled people, family members, caregivers, academics and providers. The purpose is to create ongoing collaboration with government and organisations. They are intending to look at developing a domestic exchange programme that focuses on younger leaders who are living with disability.
An Exchange Conference occurs every 18 months, which creates ongoing collaboration with government and organisations. The next exchange and conference is May 2018 in Stockholm.

Strategies / Demographic Report

The first part of this presentation was an update on the DSS Service Strategy, and a breakdown on where each of the strategies is. The service strategies cover Community Residential, Independent Living, Respite, Community therapy services, and Child development. One key change is the renaming of the Community therapy services, to 'Community Rehabilitation'. There was a sector workshop held in February 2017 and the draft strategy released for consultation in June. The second part of the meeting was around the DSS Demographic Report describing the demographics of disabled people allocated Ministry-funded disability supports by NASCs. The DSS Demographic Report is to be released in September representing a snapshot of time, it will show a break down by service groups, ethnicity and disability groups, and will be published on the MoH website when completed.
There were other presentations presented which cover such things as System Transformation/Co-Design process, the role of planning, information for families of deaf and hard of hearing children. .



A LIFE LIVED TWICE

The Autobiography of Allyson Hamblett

Allyson Hamblett is a well-known Auckland member of the CP Society. She has recently released her autobiography, “A Life Lived Twice”. The title may cause people who don’t know Allyson (and even some that do) to wonder why she chose it; but it is indeed an apt title.

Allyson was born a boy in Exeter, England in 1969 and named Alistair. One of two children, with a younger sister, the family moved to New Zealand when Allyson was about four years old. Attending the Carlson School for disabled children in Auckland may have been part of the motivation for the family settling there.

Allyson writes well - the book is very readable - describing her childhood and the dynamics within her family. Her early years were spent concentrating on coping with having cerebral palsy, but around the age of ten she had the first feeling that her gender identity and physical body were not in sync. Teenage years are full of angst anyway, but this feeling grew as Allyson matured, motivating her to seek answers to her situation.

Allyson writes movingly of the effect her transitioning from male to female had on herself, her family and her wider social network. Her struggle to find acceptance is one that many people with an obvious impairment will relate to; but in Allyson’s situation it was a “double whammy” of being accepted as a woman and with a disability.

Allyson’s intelligence shines through in her writing and her academic success.

Like many people she feels the need to help make our society a more accepting, inclusive one and, to that end, she has been an activist and an educator in both the disability and gender-diverse communities. Allyson says “for a long time I realised the politico similarities between the disability and trans communities. We are both fighting for inclusion, respect and recognition”.

Allyson shares with the reader her passion for creating music and painting. This book is a fascinating account of a life being lived with confidence and optimism.

The underlying message it leaves the reader with is “to your own self be true”.

“A Life Lived Twice” can be ordered online from: wheelers.co.nz

Alison Franklin

WORLD CEREBRAL PALSY DAY

Friday 6th October is world CP day and the Cerebral Palsy Society is planning a series of events for members throughout New Zealand. If you want to participate please email to: events@cpsociety.org.nz and let us know where you are or follow us on facebook.com/ Cerebral Palsy Society of New Zealand and join our private group "WE are here - CPSNZ World CP Day"

facebook.com/groups/CPDAYNZ

We will be sending out more info by email closer to the date.


TAKE 10,000 STEPS A DAY FOR KIDS WITH CEREBRAL PALSY

4 September - 1 October

Take the first step towards a healthier you, register now.

STEPTEMBER.ORG.NZ


Cerebral Palsy Society
Research Day
Thursday June 8th 2017

On June 8th 2017, the Cerebral Palsy Society held our second annual Research Day. The purpose of the day was to bring together members, clinicians and researchers to discuss how to set priorities for future research. Current researchers were given the opportunity to present their studies and to answer questions from members. Topics included Brain Computer Communication, 3-D muscle modeling, latest rehabilitation trends and an update on the New Zealand Cerebral Palsy Register.

The day generated discussion on how to cultivate relationships between our members and the wider research community. Focussing on how to make research more accessible and available to individuals and their families. Members provided valuable feedback on what would be most useful to them. I have listed several examples but the take-away message was that members are very interested in research and would like to see the results more readily available, especially when it comes to the latest treatments, technologies and surgeries.

- Participants requested that researchers provide detailed lay-summaries that can be distributed easily amongst members and parent support groups.
- There was a general consensus that New Zealand should form a version of a research strategy whereby future studies are measured against the desires of members for that information.
- The Society should take responsibility for issuing guidelines on how best to recruit within our membership and make research attractive and accessible to individuals and their families.
- Similarly, the Society will have a formal consultation process for reviewing research that we are asked to distribute to our membership. This is to ensure that the research has considered practical ramifications of study participation such as the need for transport or accessible rooms.

- Amy Hogan

ANNUAL GENERAL MEETING

Sunday 29th October

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

Will be held on Sunday 29th October 2017
starting at 2pm
at 14 Erson Ave, Royal Oak, Auckland.

Remits for consideration and Nominations for the Executive Board must be sent to Gilli Sinclair, Cerebral Palsy Society, P.O. Box 24759, Royal Oak, Auckland, 1345 to be received no later than 4pm on Friday 22nd September 2017.

This year, the agenda, remits and Board nominees information will be sent out by letter by September 29th. All financial information, minutes, President's report and agenda will be available online by October 19th; at the AGM or you can call the office and we will send you a copy.

Everyone is welcome to attend, ask questions & share ideas.

2017 ANNUAL GENERAL MEETING
Sunday 29th October

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

Will be held on Sunday 29th October at 2pm at Kauri Room,

CCS Disability Action Building, 14 Erson Ave, Royal Oak, Auckland.

Remits for consideration and Nominations for the Executive Board must be sent to Gilli Sinclair, Cerebral Palsy Society, P.O. Box 24759, Royal Oak, Auckland 1345 to be received no later than 4pm Friday 22nd September 2017.

The agenda, financial report etc. will be available at the AGM and on our website www.cerebralpalsy.org.nz

Remember you must be a financial member to vote.

✂ --

NOMINATION FORM

Nominations for the Executive Board of the Cerebral Palsy Society of NZ Inc, 2017

Name of Candidate: ____________________

Signature: ____________________

Name of Nominator: ____________________

Signature: ____________________

Name of Seconder: ____________________

Signature: ____________________

Points of interest:

- Nominations and Remits must be received by Friday 4pm on September 22nd 2017
- The candidate, nominator and seconder must be current financial members as of Friday 22nd September 2017
- All candidates must supply a small biography of 200 - 250 words and a photo of themselves
- Please return Nominations and Remits to Gilli Sinclair, Cerebral Palsy Society, P.O. Box 24759, Royal Oak, Auckland 1345.

THE BIG meeting

The Cerebral Palsy Society of New Zealand's Annual General Meeting

The AGM is not just a formality but a chance for members to give honest feedback in an open forum, participate in decision making process for board members and have a say in the direction we take for the year ahead. For CPS to truly be the voice of people with Cerebral Palsy and their families members need to be actively involved.

The key AGM agenda item is Board Member elections. Nominees profiles, with the agenda and remits for consideration will be mailed to all members by letter before September 29th. If you want to participate but can't attend you can still participate in the election process by sending your Proxy (vote) Form (it will be sent to you on the 29th) or you can call the office and we will send you a copy.

Sunday 29th October

CPS ANNUAL GENERAL MEETING see page 22 for more information