

The Review

August 2016



The Official Magazine of the Cerebral Palsy Society of NZ Inc

Cerebral Palsy Society of NZ

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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 NZ.

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Stepember Countdown

The countdown is on to Stepember 2016; this is the second year that the Cerebral Palsy Society has taken part in this global fundraising event, and this year is going to be bigger and better than ever. Globally nine countries participate in Stepember. As it is a global challenge, our focus is the same which is getting people moving and to raise funds for Kids, Youth and Adults living with Cerebral Palsy. As a member of the CP Society of New Zealand, we ask you to join us and take part by adding some movement to your day. All members and their families are invited to join the CP Members' team, and by using the code 'members', your team will receive complimentary registration.

Rally the troops in your local community, by becoming a Stepember Community Ambassador. Community Ambassadors will help us spread the Stepember message throughout the country, by promoting Stepember within your local community. Perhaps you could tell your local businesses, sporting or church groups and schools or just get your friends involved. Stepember is an excellent way to get people moving, and educate the community about 'Cerebral Palsy'.

All Stepember Community Ambassadors will receive a t-shirt, shoelaces, a Stepember donation box, posters, postcards and an 'Activity Tracker' which can be used to start a raffle prize pack, to help raise money.

If you are keen to become a Community Ambassador, please contact National Stepember Manager Shelly Reilly via email at shelly@cpsociety.org.nz

Stepember kicks off on the 1st of September, and you can log your steps/wheels daily. You can also convert 40 other activities into steps, including boccia, horse-riding, swimming and yoga.



Maddie signals the start of Stepember

Last year's Stepember enabled the Cerebral Palsy Society to enhance the programmes we offer to members. We also had the opportunity to begin work on several areas identified by the members' survey last year. The main areas members thought we needed to look at were improving support for families with newly-diagnosed children; providing social events for young people, Internships; looking at areas of greater need-respite for young people and after school activities. Also the Stepember money has allowed us to look at the new "Dream" programme which supports members aspiring to do whatever they choose.

So don't be shy, grab three friends and form a team today. Get your workplace involved. Just register online at www.stepember.org.nz and use the payment code 'members' to join the Cerebral Palsy Society Team for free.

News From Headquarters

Welcome to winter!! I hope you are all keeping well and healthy this winter and enjoying the colder weather. Thank you to all of you who have responded to Steptember, the Events, the new Dream Concept and the Coffee Clubs. It is wonderful to see so many members attending and participating especially as the weather gets cooler.

Board news:

The Cerebral Palsy Society Board is focusing on overseeing the improvement of programmes for current members as well as ensuring the long term support for members including a legacy for future generations. To ensure we are in the best position to provide future support, as well as maintain and improve on what we are currently doing, the Board has undertaken several external and internal reviews of Operational and Governance aspects. These reviews have identified best practice in Governance as well as reviewing the skill, gender and geographical mix and gaps within the board. (e.g. Human Resources, sector knowledge and social media). Having identified the skill base and gaps, the board has undertaken robust and proactive succession planning and embarked on vigorous process to fill vacancies based on current skills and diversity needs.

We are delighted to advise you that we have co-opted two new Board members to provide opportunities for them to increase their understanding of the CP Society Board while we utilise the skills they bring. This will also permit the CP Society Board to make solid recommendations at the AGM.

Michelle Hamilton



Hi, I'm Michelle and I've recently had the great pleasure of being co-opted to the board of the Cerebral Palsy Society.

I live on Auckland's north shore with my husband (Nick) and two boys (Thomas aged 9 and Lachlan aged 4), we are excited to be adding to our family in a couple of weeks when we bring home our new Airedale terrier puppy (Tilly). The family keep me pretty busy during the weekends, fitting in time to go to the gym (I have CP so keeping active is a must) and time with friends in around sporting commitments in a house full of football fanatics can be a challenge.

During the week I work as the Chief People Officer at NZME, home of the NZ Herald, Newstalk ZB, Radio Sport and music radio brands like The Hits, ZM, Coast, Flava and my personal favourite radio Hauraki. My role with NZME is remarkable in that no two days are ever the same and I definitely don't need to get better work stories with around 2000 highly creative people all across NZ to work with.

I look forward to meeting and getting to know other members over the coming months.



News From Headquarters

Sally Thomas



I am thrilled to have been co-opted onto the Board of the Cerebral Palsy Society and am looking forward to supporting the good work that they do. I am the parent of four lovely men, one of whom has Cerebral Palsy – Alex is 29 years old. He has received amazing practical support from the Society over the years – it is great to see an organisation that operates for the benefit of its members.

A little about me. I have worked in the disability sector for over 20 years in a number of roles. Firstly as Manager of the early intervention programme at Conductive Education Canterbury; Project Manager for “our stories” a joint IHC/CCS Disability Action community awareness project; a development role with Lead School Transition service supporting adults with disabilities leaving school; Service Coordinator at CCS Disability Action in adult services and very recently National Coordinator for NZ Foundation for Conductive Education. I have represented the CP Society on the Ministry of Health Disability Consumer Consortium for four years (retiring last year); have been on the Local Advisory Group of Enabling Good Lives for three years (retired last week!) and at the same time retired as a Board of Trustees member from Ferndale Special School. This has freed up some time to invest with the CP Society and my other passion – Arts Integrated – a performing arts programme for people with disabilities in Christchurch.

I feel really lucky to have been involved in such a cross section of disability and hope that these experiences will benefit the Board by providing a really good overview of the needs and issues for young families with babies right through to adults.

I am looking forward to meeting other Board members and making a difference in the lives of New Zealanders with CP!

Another Board opportunity:

Another key area highlighted in our review process was the value of having a member on the board who brings the perspective of the future generations. We would like to encourage a young person with CP to apply to the board. You will need to have an analytical mind, enjoy robust conversation, be interested in governance and reflect the CPS values. If you are that young person, please send your CV or a paragraph about yourself to Gilli Sinclair gilli@cpsociety.org.nz

The Office

We are sad to lose one of our Interns to paid work. Grace Hwang has been a wonderful Intern and has helped us out so significantly over the past eight months. We are sad to see her move from the office as she has been an enormous help for us but delighted to know she is moved onto paid work - her new organisation will be lucky to have her.

Welcome To Our New Fundraisers

Fundraisers:

The Cerebral Palsy Society is in an excellent financial position at present due to great fiscal management by the Board. We are in the fortunate position of having a legacy fund which has been invested and the interest is used to fund some of the programmes. However our programmes cost more than the interest from our investments. Over the past year, we have committed to looking at ways we can futureproof our organisation to ensure we maintain what we have, but also allow a sustainable future. In order to start this process, we have employed three new people to fundraise for CPS. We are really excited about the opportunities this fundraising brings and looking forward for them to meet and work with you all.

Bronwyn Gibson



Bronwyn joined the Cerebral Palsy Society fundraising team in July having more recently spent 4 years in corporate marketing, communications and fundraising for SPCA, SPELD and Laura Fergusson Rehabilitation where she oversaw the design and implementation of their development and digital strategy including the successful rebranding of services.

"I hope I can bring my forward-looking, growth hacking, nothing is impossible attitude to CP" said Bronwyn "It is a great privilege to join a team of such passionate, responsive and enthusiastic people who are working hard to support their members to have fulfilling lives and

remove barriers to independence."

Bronwyn has more than 20 years' experience in business development and corporate communications as a Creative and Marketing Director producing products, campaigns and programs for TVNZ, NZ Herald and other major brands, government departments, and leading charities.

Martin Pepperell



Martin has worked in advertising and marketing, sponsorship, grants and corporate social responsibility throughout most of his career. He has established innovative partnerships between organisations and always seeks a genuine win:win outcome to ensure enduring working relationships.

Martin is passionate about using his business skills to help support organisations achieve outcomes in the not-for-profit sector. Martin says: "I am delighted to be working with the CPS team to help secure ongoing funding for the benefit of our members."



Welcome To Our New Fundraisers

Sarah Rodgers



Sarah is originally from the UK and moved to NZ just over a year ago (via Australia) with her Kiwi husband and wee boy.

She has been a fundraiser for over ten years and is constantly amazed by the dedication and passion of the people she works with, and the generosity of the supporters who so obviously care about the cause they choose to support. "That's what makes my job so exciting and rewarding."

Sarah is looking forward to helping to raise the profile of Cerebral Palsy and the CP Society in New Zealand, and to growing the capacity of the Society to support our members.

Locker Room Fundraiser For CE

Conductive Education Taranaki Trust recently held a very successful dinner event "The Locker Room" to help raise funds and our profile in our community to realise our goal of offering this fantastic intervention service to our region.

The evening was presented by NZ CE Patron Wayne Smith and sporting personality Phil Gifford (Loosehead Len), both did a great job involving the 100+ crowd in learning about professional rugby and enjoying some great sporting banter. Our group was fortunate to raise \$19,500 from the evening through amazing donated goods including a pair of Beauden Barrett's boots and the premier item a signed 2015 Rugby World Cup jersey! This amount is a significant step towards our immediate goal of raising \$200,000 to establish our operation.

Conductive Education Taranaki Trust is currently working with Ministry of Education and local funders to ideally be able to offer Conductive Education in 2016, there is much research and discussion involved to achieve this. Our



All Black coach Wayne Smith & sporting personality Phil Gifford with Conductive Education Taranaki families

initial aim is to establish a pre-school and school (0-14yr) service. We have fantastic support from our local community and are currently gathering Expressions of Interest from potential users. Although we have a reasonable database of people that are in need of the service, we would also like to extend a welcome to NZ CP Society members to join the database - if you or someone you know in the Taranaki/ Whanganui region could benefit from Conductive Education please contact us on cetaranaki@outlook.com.

Allied Medical Launches New Website

Allied Medical has been fostering relationships within New Zealand's Healthcare community since 1998.

In February this year they launched an exciting new website. End users can now request a product demonstration, browse, select and compare items such as power wheelchairs, seek up-to-date information about funding eligibility and tap into frequently asked questions about a range of products. They can also take part in a live chat option from 8am to 5:30pm every Monday - Friday. This is a great tool for general product enquiries and connects the user up with one of their friendly Customer Support team who can also be contacted via a free phone number - 0800 31 61 81.

Allied Medical's primary goal is to provide its website visitors with quality rehabilitation solutions, information and support and it has certainly provided the quality. Digital Marketing Co-ordinator Jordon Milroy says that pulling together three outdated websites into one modern website which is usable on the complete range of mobile devices is a fantastic result.

Allied Medical product range is extensive including wheelchairs, wheelchair seating and accessories and a range of scooters. They also have walking aids and a range of aids to daily living which include such items as elastic shoelaces, pill crushers and kettle pourers.

One recently launched product is the GoTon Floorsitter which, as it says on the website "puts little ones at the heart



Allied Medical website is now usable on a complete range of mobile devices

of the fun, letting them play on the floor with pals. Firefly developed the Floorsitter accessory in response to feedback from the Community. Once the GoTo Seat has been attached, the Floorsitter has two different recline options (10⁰ and 20⁰), great for facilitating weaker head control, especially when combined with the advanced headrest."

The company has come a long way from when the daughter/father combination of Katie and Ken Noble started the business back in 1998. With a team of more than 25 people who cover the entire country, they continue to grow and add new products to their already extensive range. Katie is now the Managing Director and takes great pleasure in seeing people moving about their daily lives using Allied Medical products. "When I am out and about it's great to see people having the best life possible using the products we supply," said Katie.

The links to Allied Medical's Facebook and Instagram platforms can be accessed by visiting www.alliedmedical.co.nz to retrieve the latest content including photos and brochures.

Conference Challenged Boundaries

Recently I was given the opportunity to represent the Society at the 2016 International Cerebral Palsy Conference in Stockholm, Sweden. A beautiful city hosted a stimulating and incredibly engaged meeting of CP researchers from all over the world. The credo for the conference was 'Challenging Boundaries' and in the four-day meeting was a comprehensive overview of the latest theory and practical applications for not only living with CP but living a life where your mobility or speech don't necessarily restrict your opportunities. There were close to 1000 delegates from over 66 countries. The aspect I found most worthwhile was the emphasis on all dimensions of living with CP from examining the underlying causes of CP at a biological level to examining living well throughout the entire lifespan.

Causes and Neonate Care: Respected CP researchers Iona Novak and Sarah McIntyre from Cerebral Palsy Alliance Australia presented a lecture on the latest research in both the prevention of CP and the minimizing of the severity of the symptoms. Interestingly, the Australia CP Register has reported a small reduction in both the numbers of people with CP and the severity of symptoms that individuals are displaying on a whole. The techniques discussed include ways to reduce inflammation in the brain (Cell Lines, Cooling Caps). Neuro Imaging to track the different nerve conduction and to monitor neuroplasticity.

CP and Paediatrics: There were three main highlights for me in this area. The first is the emphasis on communicating accurately with children and promoting



Stockholm at night

kids and families' rights within a medical setting. Second was the development of meaningful diagnostic criteria that separates different levels of CP in particular areas, for example, hand and feet function, the intensity of the movement disorders (dystonia), and differing brain structures so that treatment can be more tailored. Furthermore, the notion was posted to diagnose children early as 'at risk of Cerebral Palsy. 86% of parents reported to suspecting CP or actively researching the condition before the possibility was formally discussed with a specialist.

Adulthood: The central focus of the adult-based research was keeping individuals as well as possible and enabling them to maintain as much independence as possible. One of the main features was understanding the complex relationship between pain, functionality and fatigue and overall health within bones and muscles. In particular, how best to maintain mobility for essential tasks such as transferring, or staying comfortable in a seated position. Similarly, an excellent talk emphasises the importance



Conference Challenged Boundaries

of making suitable equipment that it is appropriate for a young adult or adult. For example, - 'functional fashion' - these are not only 'shrunk and pinked' but brought into real world context such as leg braces that can be worn discreetly under clothes or rehab equipment

International Perspectives: One of the most interesting aspects of the conference was perspective from different countries. I attended lectures from 15 countries - Israel, Norway, Finland, England, Sri Lanka

and Bangladesh. Topics like international cooperation and treating CP with limited resources were discussed at length.

I am collecting all the papers for the conference and will be writing a series of articles on specific areas (SDR and Stem Cell Treatments). If you would like more information please feel free to email.

Amy Hogan

amy@cpsociety.org.nz

Upcoming Auckland Events

Thanks to everyone who came to the Trots at Alexander Park raceway. A few lucky punters made a small fortune. Well a few extra dollars anyway. Keep an eye out for further events.

One of the highlights of the year will be our Christmas dinner which is going to be held in December at the Sorrento (Cornwall Park). Dates of other activities are yet to be confirmed.



Auckland Mobility Transport Limited

This year Gary welcomes his son Jason into the business.

Both look forward to another 17 years of servicing the disability sector.



- 17 years service
- Owner operators
- Transport on time
- NO booking fee
- NZQA approved drivers
- Competitive rates
- Hoist vehicles

Ring today - Bookings: 09 827 7032, Gary: 0274 830 746 Jason: 021 441 315

Weekend work should be pre-booked to avoid disappointment

CP vouchers welcomed

Vaka Tautua Discards Labels



The majority of Vaka Tautua's Auckland staff and volunteers

The lovely people at Vaka Tautua, a charitable organisation that aims to help improve the health and wellbeing of Pacific people in New Zealand, do not believe in labels. The areas they focus on are Pacific Mental Health, Disability, and Older People's Services but as communications officer Anele Bamber says they are all just "our people". After talking to Anele and her colleagues National Regional Manager Kristina Sosele and DIAS (Disability Information Advice and Support Services) coordinator Tina Mataiti, it didn't take long to realise that flexibility is the core ingredient to each service.

Vaka Tautua run community programs and services that provide support especially to Pacific older peoples, those living with disability and those seeking support for mental health. They support people who are impacted by a range of social issues such as the cost of rent, the flow on effect of poor home insulation, issues of overcrowding in homes and inadequate mobility equipment and accessibility into their homes. They also help to educate people over social issues such as mental illness being treatable.

To help in the area of education they run regular programmes such as a free eight week course on financial literacy which aims to support Pacific families with a disabled family member on their journey to financial capability and other support programs that deal with the care of the elderly and disabled. The latter programme includes how to provide healthy meals. Vaka Tautua proudly announced that their financial literacy programme which has been completed by families living in Manurewa, West Auckland, Otahuhu, Mangere and Otago, was recently recognised at the The NZ Federation of Disability Information Centres Conference and was awarded the 'Diane Rangi Innovation Award'.

Vaka Tautua is all about answering the question "What can we do to help?" and to talk the people through the process of getting that help.

For further detail call them Toll Free on 0800 825 252

You can also connect with them on their Facebook page: www.facebook.com/vakatautua

The Day Was Full Of Wonder

Thursday, July 21st in Auckland was definitely touched with a large dose of magical fun at the first CP Society Children's Pirate and Fairy Party.

This was a perfect opportunity for magically inclined members, families and staff to dress up and have a good time. There were glittery fairy outfits, buccaneering pirate creations, costumes that looked like the pirate hordes had arrived and others that looked like a fairy emerging straight from a forest flower.

Then with a big fairy "hello" the two fairy hostesses from Fairy Shop NZ arrived to share magic, wonder, and merriment, enchanting the guests both old and young.

With so many fairies and pirates in attendance, there was much blowing of bubbles, party games and posing for photos with excited children and equally enthralled adults. Little tummies were well catered for too, with luscious food from Lee's Family including cute kiddie's mocktails with umbrellas.

"What a great party, the kids had an amazing time," said Lisa Struthers, "great to meet other families too."

According to Pink Fairy "being a fairy is a lot of fun". "We get to go out and make people happy and have a great time doing it." The fairies hope to host the next party soon in Christchurch.



"Thanks to all those who put the hours into making this happen," said Caroline Smeed, "My boys had a fabulous time!"

Parties like these are important experiences for children to have, it is uplifting to see so many happy faces.

Ann Styles thanked the CP Society "family" for a wonderful day. "We all had a great time, so nice to catch up with other families."

Then with a wave of a wand and a fairy goodbye the fairies were gone - until the next time!!!

Photo credit: Big thank you to the photographer Sharlene Ferguson @Focal Point Photos

To see more photos of the day go to [facebook.com/cpsocietynz](https://www.facebook.com/cpsocietynz)



2016 Annual General Meeting

Sunday 16th October

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

Will be held on Sunday 16th October at 2pm at Kauri Room,
CCS Disability Action Building, 14 Erson Ave, Royal Oak, Auckland.

Motions for consideration and **Nominations** for the Executive Board must be sent to Gilli Sinclair, Cerebral Palsy Society, PO Box 24759, Auckland 1345 to be received no later than 4pm Thursday 8th September 2016.

The agenda, financial report etc. will be set to each financial member by October 2nd. Remember you must be a financial member to vote.

NOMINATION FORM

Nominations for the Executive Board of the Cerebral Palsy Society of NZ Inc, 2016.

Name of Candidate: _____

Signature: _____

Name of Nominator: _____

Signature: _____

Name of Seconder: _____

Signature: _____

Points of interest:

- Nominations and Resolutions must be received by 4pm on September 8th 2016.
- The candidate, nominator and seconder must be current financial members as of September 8th 2016.
- Please return Nominations and Motions to Gilli Sinclair, Cerebral Palsy Society, PO Box 24759 Royal Oak 1345.
- **A reminder.** At last year's AGM, the Cerebral Palsy Society constitution was changed so the Board can nominate their own officers (President, Vice president, Secretary etc.) from the board members elected by the society members. This constitution change is reflected in the nomination form change. The other key change was a two years' term for board members.



Latest CP Developments

As I have written in my previous article one of the great highlights of the conference for me was that the event brought together researchers from 66 different countries from Iceland to Israel to Indonesia. This collective means that aside from creating immensely interesting discussions and fostering a genuinely global CP Research Community this has a practical advantage. The conference has access to many different CP Registers or population surveys such as the Norwegian CP Population Study or the Icelandic Wellness Study. Therefore they can report very accurate and comprehensive information on the latest CP innovations and provide evidence on aspects that have gained considerable attention such as Stem Cell Research and Selective Dorsal Rhizotomy.



Amy's on the move with walking bike

Latest Developments: Protecting The CP Brain

For a long time, it was believed that once the brain was injured there was little to nothing that could be done to minimize or reverse the damage. In other words the best that could be hoped for is managing the symptoms. However, we now know this not to be true. The pathways within the brain can be influenced and altered by a mixture of drugs, anti-inflammation techniques, temperature, and biophysiological approaches – the earlier this begins, the better for the individual. The procedure now is 1) CP Risk Assessments 2) Scanning the Brain 3) Outlining Severity

We are also developing an understanding of the CP Brain. Researchers are looking into what an injured neonatal brain actually looks like on the scans. What parts of the brain are injured and where are the most severe injuries? What are the common patterns amongst CP brain scans across the world? The result of this insight is that interventions are being targeted in 3 main

areas 1) Producing protective measures for mothers identified as risk factors (i.e. prematurity) 2) Reducing general brain inflammation 3) Designing targeted interventions for specific areas of the brain or the neuro pathways (reducing cell death.)

One of the most important themes addressed was providing pathways for parents well before formal diagnosis so that they can get involved as early as possible by 1) Promoting function in day-to-day life over clinical settings 2) Family Friendly, financially viable, interventions which are fun and feasible. Several examples of these were presented; in particular for hemiplegic CP and severe CP.

Latest Developments: Enhancing Function with CP

The strongest theme was the notion of promoting function and wellness ➡

Latest CP Developments

for as long as possible. For example, maintaining the ability to transfer throughout the lifespan or keeping the best lung and diaphragm health if you are primarily using a wheelchair. One of the most engaging strategies was to present individual examples of people who have different kinds of CP and how their various function needs can be met by Physiotherapy or Occupational Therapy. For example, a case was presented in all the quality of life measures for a young adult with Level 5 CP who experiences seizures – the Clinical Outcomes vs. Functional Outcomes vs. Patient and family perspectives were all examined.

1. Clinical Realities: What the body looks like – how well the muscles move
2. Functional Goals: What is the individual able to do
3. Personal Goals: Are they able to do what they want to do.

Latest Developments: Enhancing Adulthood with CP

One of the strongest themes at the conference was acknowledging the complexity of living with CP as an adult. Principal concerns included 1) promoting independence 2) successfully moving

beyond the family home 3) access to employment or community 4) managing complications of chronic pain. A Norwegian study group has developed a strategy for managing fatigue and pain in the workforce. 34% reported some level of pain 54% reported pain by the age of 37.

Latest Developments: Stem Cells

Stem cells have received considerable public and media attention. The general consensus amongst CP researchers is that although stem cells are a new science, there is an ever-increasing body of research that supports the idea that properly administered the cells can make a difference to CP. Specifically, the cells did promote some neuro regrowth in the individuals who were administered doses in clinical settings. The status of stem cells is summarised as follows: 1) The methods for implementing stem cells are becoming more refined 2) The amount of stem cell research is increasing each year significantly. 3) The Risk-Benefit profile is acceptable (risks can be managed) 4) The understanding of how to produce and maintain quality stem cells is improving significantly

By Amy Hogan

Mt Eden Summit Access

Since Auckland's Maungawhau/Mt Eden summit access has been restricted due to cultural and environmental reasons, around 70 individuals with limited mobility have accessed the summit. Visitors with limited mobility can request a temporary access code to gain entry to the summit road by calling the Auckland Council customer service centre on the day of their visit.

Visitors will be asked to provide their Total Mobility scheme or Mobility Parking Permit number to verify eligibility. Codes are only distributed to individuals who can not physically walk to the summit. People can call the Council on either 301-0101 or 379-1340.



Happy Birthday SAB

On Friday July 1st 2016 South Auckland Boccia (SAB) celebrated its 20th Anniversary at the Papatoetoe Town Hall. My how time flies!!! As the invitation, put together by long-serving secretary Margaret Thomson, stated, "Come and share memories. Come and roll a few balls or ends. Join in this historic occasion of the past, present and the future of the oldest boccia club in New Zealand."



Long serving SABA members reflect on 20 years

Many Ex players and supporters took up the invitation and the memories did flow. The journey of the Club's Paralympians is something to be proud of but there are many more purely Club memories to treasure. Who could forget the way the late Rodney Arts proudly wore his medals after he won at either regional or national level, or the way our local club competition organised by the late Ian Lyon was so intensely fought.

How about the time when SABA so successfully hosted the NZ Nationals, I think that was the time I had my most painful memory when Kaylene Dobson soundly beat me in a match. I couldn't hit a barn door that day. She played well though. Probably the most fond memories came from the trips around the country, where SABA members' won gold, silver and bronze at various tournaments. Those were the days, eh!!!

Boccia New Zealand President, Harvey Brunt hit the target when he said in his speech that Boccia was a reason for CP people to gather. Back in the day there was no HQ and the sport provided a meeting place. SABA patron, former MP and now local community board member,

Ross Robertson spoke of how important the word "team" was. All Clubs go through rough patches but as long as we stick together the Club will pull through he said.

Past members will be pleased to see the tournaments are still going. The South Island Champs were held over the weekend 16th-17th July. The current Director of Boccia reported that 21 players competed across 4 classifications. On the Saturday a round robin was played and Sunday was the finals competition. Players came from all over the country including Auckland, Waikato, Canterbury, Otago, Queenstown and Invercargill.

Another exciting addition to the Auckland Boccia scene is the Auckland Interclub Boccia competition. The first one was held on Sunday 24th July at the Papatoetoe Town Hall with a contest between the SABA and Onehunga Boccia Clubs.

May the Boccia balls continue to roll around the courts.

Ross Flood



Conductive Education – Support For CP

You can be left not knowing where to turn when your child is diagnosed with Cerebral Palsy but there is lots of help out there – you just need to know where to access it!

Looking back at our experience there isn't much that we would change – the best thing has been our involvement with Conductive Education (CE). Alex was a first day pupil at all of the Christchurch CE centres - the Early Intervention programme, Addington Primary, and then Cashmere High School. We think it is remarkable how much he learnt during that time and the positive impact CE has had on his quality of life – right up until now at 29 years old!

CE is a holistic programme which works on all areas of development – motor skills such as rolling, crawling, walking, climbing stairs; hand function; cognitive skills; communication and social skills – actually in a nutshell it helps people gain functional skills that will give them more independence – something that most of us take for granted. It works well to be able to come to one place and get all of your major needs met, potentially lessening the number of appointments you need.

CE taught Alex really practical skills that have helped him have more control over his life and he is still surprising us (and himself) with new skill development. The great thing for me personally was the support I got from the other families and the highly skilled CE team of specialists. What I learnt from working with Alex in the programme as a pre-schooler continues to help us problem-solve solutions all these years down the track.

After a long break from CE since leaving Cashmere High School, Alex has recently joined the adult programme – he really looks forward to this – especially the



Alex (middle) works out with his mates

social side of it! When Alex left Paediatrics at age 17 we seem to have fallen off the radar of other professionals and not being trained to recognise issues ourselves we have felt the pressure of perhaps missing something important. It is great to know that Alex is now being monitored by a Conductor - a highly skilled professional who is specifically trained to support his type of disability. Alex has good health so doesn't need to visit his GP (who admits that some things are beyond her level of expertise) and because he has such fantastic health – it is a very rare visit!

Conductive Education has evolved over the past 25 years and is now available in Christchurch for babies through to adults of any age, which is great.



Conductive Education – Support For CP

I have recently taken over the role of National Coordinator with NZ Foundation for Conductive Education and have been connecting with our affiliated centres throughout the country. We are so lucky to have early intervention programmes in Auckland, Hamilton, Wellington and Christchurch; primary school facilities in Hamilton, Wellington and Christchurch; a high school facility in Christchurch; and adult programmes catering for a wide range of people (including those who have had strokes, Parkinson's and head injuries) in Auckland and Christchurch.

NZFCE are also pleased to be working with a dedicated group of families in Taranaki

who are looking at establishing an early intervention and primary school centre in New Plymouth.

If you are interested in knowing more about Conductive Education or want to connect with any of our centres, please give me a call on 0800-169-323. I look forward to hearing from you.

You could also visit www.conductive-education.org.nz or look for New Zealand Foundation for Conductive Education on facebook.

Sally Thomas (and Alex)

The Diving Bell and the Butterfly

By Jean-Dominique Bauby

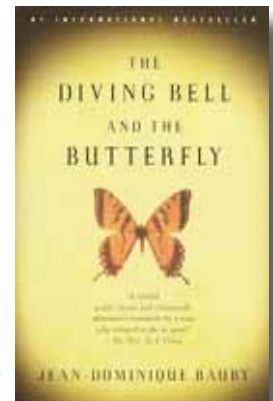
Review by Elliot Yates

Jean-Dominique Bauby is amongst those who have written from their experiences on disability upon paper. Due to the crash he suffered in 1995, he had locked-in syndrome, back then an obscure disability. He used to be an editor of a women's magazine. (He was successful enough to reach China by his own account.) He lived only two years after the crash; departing from the world with much grief, love and fondness from those who knew him.

In spite of all this, he managed to write this memoir. What is remarkable about this book is not that communication was even established - lending a hand to the process of writing this book - but that it managed to be an expression of what it means to live with a disability, whether it be from birth, or accident. We get a montage of struggles with drool; sardonic thoughts about hospital nurses; a mental struggle to reconcile the worlds of being able-bodied and being disabled; seeking a sense of calm and identity.

You can see plainly that Jean-Dominique does regard disability as a misfortune, but he also saw it as an opportunity to grow and be stronger for it. Having a disability from birth is different to disability by accident, and one perceives he has had remarkable mettle to be able to adjust as well as he could in these circumstances.

This is a book people should read, indeed.



Parafed Auckland: 50 Years Old



New Zealand's oldest and largest disability sport organisation is turning 50 years old in 2016. For those who have been associated with Parafed Auckland over the years the organisation has planned a great celebration to mark the occasion. It has booked the Guineas Room at the Ellerslie Convention Centre, on the evening of November 12th at the indicative cost of \$32.50 which includes a three course meal, table wine, and entertainment. The evening consists of a full dinner, cash bar, entertainment, speakers and presentations. It would be hard to find a better deal than this. We will keep you informed as more details emerge.

Current CEO of Parafed Auckland – Disability Sport Hamish Meacham reflects on the organisation history.

"Starting as the Auckland Paraplegic and Physically Disabled Association in 1966, our goal was to foster games, sports and recreation for paraplegics and the disabled, as well as to cater for their general welfare. In that same year, the Association sponsored and organised a national team of wheelchair athletes to compete at the Commonwealth Paraplegic Games in Jamaica. Two years later, the Auckland Association also combined with fellow organisations to send a team to compete at the Paraplegic Games in Israel. Our formation was closely followed by Otago-Southland, and eventually led to formation of the New Zealand Association (now operating as Paralympics New Zealand).



Sports for the physically disabled, especially those in wheelchairs was considered fairly radical at the time, but high profile athletes such as Pompey Heremiah worked hard to overcome stereotypes as well as being a role model for younger athletes. A milestone moment in the history of the organisation was the building of the Parafed Gym at the Otara Spinal Unit in 1977; this not only gave our athletes and teams a permanent home, but it also proved a huge boost for all disabled sport, as patients in the unit where more often than not recruited to join in on the sports taking place.

Fast forwarding to 2016, we now oversee a network of 15 clubs and activity providers – catering to more than 300 active athletes. We plan on celebrating our 50th Anniversary in style this coming November, hosting a dinner for all current and former athletes, coaches, volunteers and friends.

If you would like to receive more information (which will be available in the coming months) please call us on 09 270 2503 or email office@parafedauckland.co.nz "

Making Track Wheelchair-Friendly

During March, the Department of Conservation paired up with the Halberg Disability Sport Foundation and Hokitika woman Merle Bradley to undertake a wheelchair accessibility trial on the Abel Tasman Coast Track. The track was chosen because it has been developed to a high standard, and also because of the track's water taxi service which meant that transporting gear and supplies could be done with a minimum of effort.



Merle Bradley trying out the ViMo wheelchair

Being outside in beautiful natural environments is good for everyone - it's associated with lower blood pressure, faster healing, lower rates of depression, better mood and many other benefits. Consequently, we want as many people as possible to enjoy the outdoors – and that includes people with limited mobility.

We were inspired to hear of people undertaking substantial adventures in wheeled mobility equipment and we wanted to get a sense of what might be involved for someone who would undertake an adventure on a DOC track. To assist us in our trial, we found a keen participant in

Merle Bradley, a Hokitika woman who was diagnosed with Motor Neurone Disease in 2014. Merle, along with her family and friends, who supported her on the Abel Tasman Coast track and helped us gain an understanding of the challenges faced by someone in a wheelchair.

Merle had recently returned from a world trip where she learnt about the frustrations experienced by many when using a conventional wheelchair on a less than a perfect surface. Merle returned to New Zealand with a determination to find a chair that she could use on adventures, which led her to inventor and engineer Peter Thompson, who has designed the ViMo wheelchair, which is designed to be easily transportable, and easy to push on rough and uneven surfaces. Peter is also experimenting with an electric version of the ViMo, which a user operates. The trial was undertaken in conjunction with the Halberg Disability Sport Foundation who provided a 'Trail Rider' all-terrain wheelchair for the trial. The Trail Rider chair has a single central wheel and requires a ➡



Merle Bradley rests from her adventures

Making Track Wheelchair-Friendly

person at each end to push and pull.

During the trial three “off-road” wheelchairs were tested, two nights were spent in DOC huts, and a total of 30 kilometres were covered. A lot was learnt over the three days, and DOC now has a greater understanding of the requirements of people who have limited mobility. The track is one of our easier Great Walks and is finished to a much higher standard than most tramping tracks, but the terrain in places was still challenging and at least two strong people were required to manoeuvre the chair. Still, the trial showed that it could be done, albeit with a reasonable level of support.

We had quite a bit of feedback after the trial due to the publicity it generated. People with differing levels of mobility, and different reasons for wanting to get out into nature got in touch to tell us about what they'd like to see for improved accessibility. This has all been very useful, and has helped us to plan improvements to increase accessibility.

The provision of good information on the facilities at an accessible site was shown to be important. We've updated our website so that people can use a filter to determine which tracks in their chosen region may be suitable for a wheelchair user. There are currently 52 DOC tracks in that category. We are also liaising with Halberg Disability Sport Foundation and a company that specialises in auditing accessible facilities so that we can develop a framework for assessing our facilities. We want to better describe the experience that people with disabilities will have at a place.

We're a ways off having accessible long tracks, but with Merle and her friends and family and some specialised equipment we've shown that it is possible to have

a substantial adventure in the great outdoors.

Merle says her trip and the associating planning for it “bought a big zest and spark in her life” and the confidence to get out and about. She's now taking every opportunity to try out new places in her ViMo chair. The Hokitika Lions and Rotary clubs bought two chairs for the town's i-Site, to be hired out to people wanting to explore the West Coast's cycle trails and other accessible tracks. Merle is sharing what she's learning on her adventures with the Hokitika i-Site, and hopes that the West Coast will become a destination for people like her who want to have a great time and enjoy the benefits of being in the outdoors.

Keep an eye on developments at www.abeltasmanguides.co.nz

Jonathan Thomas
DOC project manager

The CP Society Website

Remember to visit our website regularly

Keep up with the latest News and Notices

www.cerebralpalsy.org.nz



Your Ideas Needed For CP Day

To acknowledge the significance of World CP Day on October 5th we want your creative ideas to develop with the ultimate goal of improving the quality of life of people with Cerebral Palsy. You have our full support to explore the depths of your imagination to come up with innovative concepts to improve lifestyles. To get the juices of your top two inches flowing a couple of examples of the desired innovation are Beach Pathways and Mobility in a Box.

Beach Pathways, is the idea of making beaches accessible by providing a mat so that wheelchair beach goers can travel with ease, over the sand to the water's edge. Amy Hogan came up with the idea of the Mobility in a Box concept which is about providing mobility supplies for refugees or any other displaced people. Mobility supplies such as a set of crutches, lifting slings, seating straps, and foldable wheelchairs could be placed in a box and given to people who are most in need.

Some ideas can fit into the small scale category; such as that very practical kettle tipper that has just hit the market which is bound to lessen the risk of scorched bodies caused by boiling water; or perhaps a piece of equipment help to put on your socks. These ideas that cater for everyday life routines should not be dismissed.

The only stipulation when submitting ideas is that all concepts must fit in the World CP Day categories (so that they can appeal to the widest range of countries,) When all ideas are received, a review committee will be formed to build on the best of the ideas in time to produce in 2017.



Access Mat an example of innovation

People can submit their ideas and dreams for CP in any form they want. So the ideas can be in written form, videoed, face to face or any other way you see fit.

The World CP Day categories come under the headings of: Public Awareness, assisting others to look beyond the disability.

Civil Rights, where many people with CP lag well behind the 'majority'.

Medical / Therapeutic, improving the basic building blocks of care: cause, diagnosis and treatment. Education, the single greatest predictor of a fulfilling life and Contribution, the very human desire to make our mark on the world. All these categories need your thoughts and ideas to give a life of quality to all CP people.

Go to our home page, www.cerebralpalsy.org.nz, click on our contact link and send your World CP Day contribution or talk to one of the office staff on 0800 503 603.

Ross Flood

TA Powerchairs 100% Safer*



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

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

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

The ISO standard 7176-19:2008 measures a powerchair with an occupant seated in their chair within a vehicle in a simulated 50kph impact using a hybrid dummy of 77kg. With an average powerchair this equals a stationary mass of 220kg, at impact this increases to 3500kg. The dummy and all powerchair components are then measured for movement, stress and damage.

It is a pass or fail when it comes to your safety. No different to simulated crash tests for an occupant in a car or van. To view crash test videos for TA powerchairs scan the QR code below or visit our website.

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

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

You do have a choice - TA the New Standard



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Crash Test FAIL



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Upcoming Events

Date	City	Event
August 11th	Auckland	Research Day
August 28th	Christchurch	Casino
Sept 4th	Christchurch	Fairies
Sept 21st	Christchurch	Meet the Board
Sept 28th	Masterton	Lunch
Oct 3rd	Christchurch	Play & Pizza
Oct 12th	Hamilton	Dinner
Oct 13th	Whangarei	Lunch
Oct 16th	Auckland	CP Society AGM
Oct 19th	Palmerston North	Dinner
Oct 20th	New Plymouth	Dinner
Oct 26th	Napier	Dinner
Oct 27th	Tauranga	Dinner
Oct 30th	Auckland	Still to be confirmed
Nov 2nd	Dunedin	Dinner
Nov 3rd	Invercargill	Dinner
Dec 4th	Christchurch	Christmas Lunch
December	Auckland	Christmas Lunch
December	Wellington	Christmas Lunch

For more information on any of these events please email michael@cpsociety.org.nz

or phone 0800 503 603 between Monday to Friday from 9am to 5pm